From: Sent:	02 May 2018 10:38				
To: Subject:	PublicLiaison1-SM reedom of Information request - Royal College of Physicians (RCP) report				
Dear Belfast Health and Social Ca					
Information now exists in the pupatients identified in the Royal C Watt, following an independent	ablic domain concerning 2500 neurology patients including the letter you sent to college of Physicians (RCP) report concerning Consultant Neurologist Dr Michael review by RCP.				
The RCP report identifies a number their care and treatment following	ber of patients who should now be invited to attend a review appointment to review ng their report.				
RFI-					
1.What do you mean by "a revie	w appointment" for patients identified in the RCP report?				
2.In your letter sent to patients i patients identified in the RCP rep	identified, what do you mean by "we may need to plan further investigations" for port?				
3. In your letter sent to patients possible care and treatment"?	as identified, what do you mean by "in order to ensure you are receiving the best				
4. How much do you estimate pa imaging?	ying independent providers to review patients identified in the RCP report including				
5.Please list the all the neurologietc?	ical conditions of the patients identified in the RCP report, ie. Parkinson's, epilepsy,				
6.How many patients need to be and the reasons needed for their	e reviewed as a result of the Royal College of Physicians recommendations/report review?				
7. How many of the patients iden prior to their review appointmen	ntified have been red-flagged as potentially being misdiagnosed at this stage and nt?				
7.Please provide a copy of the Roprovided to you by the RCP (plea	byal College of Physicians recommendations/report (preferably in PDF format) ase redact all personal information from this report when you provide it).				
Please provide the following info to reports by the BBC, ITV, Belfas	ormation as it will cause no harm and it is in the public interest, and will add clarity st Telegraph, Newsletter, Irish News, etc about the matter.				
*In relation to this RFI, I am not s Consultant Neurologist identified before you provide the informat	seeking any personal information whatsoever about any individual including the d by RCP. Please feel free to redact all information pertaining to any individual ion I have requested				
Yours faithfully,					



T: (028) 9504 5888 F: (028) 9056 5553 E: publicliaison@belfasttrust.hscni.net

7th June 2018

Our ref: FOI/17951

Your ref:



Dear

I refer to your Freedom of Information (FOI) request received 2nd May 2018.

Please find below the details you requested. I hope this information is helpful.

Information now exists in the public domain concerning 2500 neurology patients including the letter you sent to patients identified in the Royal College of Physicians (RCP) report concerning Consultant Neurologist Dr Michael Watt, following an independent review by RCP.

The RCP report identifies a number of patients who should now be invited to attend a review appointment to review their care and treatment following their report.

RFI-

1. What do you mean by "a review appointment" for patients identified in the RCP report?

Any patient recalled will be reviewed by a consultant neurologist within the 12-week period between May and the end of July. A clinical assessment of the patient will be undertaken to reassure them and ourselves that their care and treatment is appropriate. If there are any follow-up investigations needed, these will be arranged within a very short timescale and a follow up with the patient will take place. Each review appointment will last approximately 30 – 45mins in line with Royal College of Physicians guidance. Any patient requiring a follow up will be contacted as soon as possible after their review appointment to arrange the next date. The additional clinics that are currently being undertaken will continue to be provided in order to ensure that there is sufficient capacity for patients to receive appointments at the earliest opportunity.

2. In your letter sent to patients identified, what do you mean by "we may need to plan further investigations" for patients identified in the RCP report?

See above.

3. In your letter sent to patients as identified, what do you mean by "in order to ensure you are receiving the best possible care and treatment"?

Please refer to question one.

4. How much do you estimate paying independent providers to review patients identified in the RCP report including imaging?

Ensuring that patients are receiving the best possible care and treatment is the most important consideration of the recall. Whilst there will be a cost associated we will not know the full extent of this until the recall has been completed.

5. Please list the all the neurological conditions of the patients identified in the RCP report, ie. Parkinson's, epilepsy, etc?

The RCP report covered the review of notes from across the consultant neurologist's practice.

6. How many patients need to be reviewed as a result of the Royal College of Physicians recommendations/report and the reasons needed for their review?

On 1 May 2018, Belfast Trust recalled 2500 patients following an independent review of patient notes relating to the work of a single Consultant Neurologist Dr Michael Watt. The action follows a review of patient notes by both the Trust and the Royal College of Physicians. The consultant is currently not treating patients. I would also refer you to our website FAQ's for Neurology where there is further clarity on some private patients.

http://www.belfasttrust.hscni.net/about/3144.htm

7. How many of the patients identified have been red-flagged as potentially being misdiagnosed at this stage and prior to their review appointment?

Belfast Trust recalled 2500 patients based on independent and expert advice from Royal College of Physicians

The Trust is to review all of Dr Watt's current and active caseload of patients to establish whether diagnoses and current treatment plans are correct.

The full picture on the extent of changed or updated diagnoses and treatments will only be ascertained at the conclusion of both the recall process and any follow-up appointments.

8. Please provide a copy of the Royal College of Physicians recommendations/report (preferably in PDF format) provided to you by the RCP (please redact all personal information from this report when you provide it).

As you will know, the Report relates to the practice of one Consultant Neurologist at the Trust, Dr Michael Watt. The full Report has been shared in confidence with Dr

Watt and the Public Health Agency (PHA), the Department of Health and the General Medical Council.

The recommendations and conclusions in the Report were shared in confidence with the Ulster Independent Clinic (UIC) and Hillsborough Private Clinic (HPC); the clinics where Dr Watt was practising at the time restrictions were put in place. This was so that those organisations could ensure appropriate action in relation to those patients within Dr Watt's practice at the time of the restrictions.

The report contains personal information relating to the doctor, whose identity is known. Since disclosure to yourself is not necessary to fulfil public interest considerations such as the need to ensure appropriate action in relation to current patients, the Trust is not in a position to provide the RCP report to you at this time.

Please provide the following information as it will cause no harm and it is in the public interest, and will add clarity to reports by the BBC, ITV, Belfast Telegraph, Newsletter, Irish News, etc about the matter.

*In relation to this RFI, I am not seeking any personal information whatsoever about any individual including the Consultant Neurologist identified by RCP. Please feel free to redact all information pertaining to any individual before you provide the information I have requested

The Royal College of Physicians report is personal to Dr Watt. We are taking action based on its findings.

If you are dissatisfied with the way in which your Freedom of Information (FOI) request has been handled you may wish to complain. You should contact Nore Villa, Knockbracken Health Care Park, Saintfield Road, Belfast BT8 8BH or alternatively e-mail:

within two months of the date of this response and your complaint will be considered and a response provided usually within 20 working days of receipt.

Should you still be dissatisfied with the outcome, you can proceed to the second review stage by contacting the Information Commissioner, The Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, SK9 5AF who will undertake an independent review. It is important to note that if you refer any matter to the Information Commissioner, you will need to show evidence of having gone through the Trust's review process to try to resolve the matter with the Trust in the first instance.

If you require any further information or wish to discuss, please do not hesitate to contact me.

Yours sincerely

Public Liaison Services Officer

From: Sent: To:	03 July 2018 15:42 PublicLiaison-SM
Subject:	Internal review of Freedom of Information request - Royal College of Physicians (RCP) report
Dear Belfast Health and Social Ca	are Trust (Northern Ireland),
Please pass this on to the persor	who conducts Freedom of Information reviews.
I am writing to request an intern FOI request 'Royal College of Phy	al review of Belfast Health and Social Care Trust (Northern Ireland)'s handling of my ysicians (RCP) report'.
The information I have request i	s deliberately being withheld by your organisation.
	and all correspondence is available on the Internet at this address: com/request/royal_college_of_physicians_rcp
Yours faithfully,	
Please use this email address for	
Disclaimer: This message and an policies: https://www.whatdotheyknow.c	y reply that you make will be published on the internet. Our privacy and copyright com/help/officers
	afely disclosing information, read the latest advice from the ICO: com/help/ico-guidance-for-authorities
Please note that in some cases p	ublication of requests and responses will be delayed.
If you find this service useful as a FOI page.	an FOI officer, please ask your web manager to link to us from your organisation's



T: (028) 9504 5888 E: publicliaison@belfasttrust.hscni.net

Date 17th August 2018

OUR REF: FOI/17951

Name: Email address:

Dear

INTERNAL REVIEW

FOI ENQUIRY RE: 17951

Thank you for your email received on 3rd July requesting an internal review, relating to our response to the above FOI request.

Following an Internal Review the Trust has updated part of our response as outlined below.

1. What do you mean by "a review appointment" for patients identified in the RCP report?

Any patient recalled will be reviewed by a consultant neurologist within the 12-week period between May and the end of July. A clinical assessment of the patient will be undertaken to reassure them and ourselves that their care and treatment is appropriate. If there are any follow-up investigations needed, these will be arranged within a very short timescale and a follow up with the patient will take place. Each review appointment will last approximately 30 – 45mins in line with Royal College of Physicians guidance. Any patient requiring a follow up will be contacted as soon as possible after their review appointment to arrange the next date. The additional clinics that are currently being undertaken will continue to be provided in order to ensure that there is sufficient capacity for patients to receive appointments at the earliest opportunity.

2. In your letter sent to patients identified, what do you mean by "we may need to plan further investigations" for patients identified in the RCP report?

See response above and for clarifications, "further investigations" refers to further diagnostic investigations.

3. In your letter sent to patients as identified, what do you mean by "in order to ensure you are receiving the best possible care and treatment"?

Please refer to question one.

4. How much do you estimate paying independent providers to review patients identified in the RCP report including imaging?

Ensuring that patients are receiving the best possible care and treatment is the most important consideration of the recall. Whilst there will be a cost associated we will not know the full extent of this until the recall has been completed.

5. Please list the all the neurological conditions of the patients identified in the RCP report, ie. Parkinson's, epilepsy, etc?

The RCP report covered the review of notes from across the consultant neurologist's practice.

6. How many patients need to be reviewed as a result of the Royal College of Physicians recommendations/report and the reasons needed for their review?

On 1 May 2018, Belfast Trust recalled 2500 patients following an independent review of patient notes relating to the work of a single Consultant Neurologist Dr Michael Watt. The action follows a review of patient notes by both the Trust and the Royal College of Physicians. The consultant is currently not treating patients. I would also refer you to our website FAQ's for Neurology where there is further clarity on some private patients.

http://www.belfasttrust.hscni.net/about/3144.htm

A total of 2329 patients have been seen with a small number of people either declining appointments, not attending, or requesting an appointment after the official end of the recall.

7. How many of the patients identified have been red-flagged as potentially being misdiagnosed at this stage and prior to their review appointment?

Belfast Trust recalled 2500 patients based on independent and expert advice from Royal College of Physicians

The Trust is to review all of Dr Watt's current and active caseload of patients to establish whether diagnoses and current treatment plans are correct.

The Department and the Trust will provide information about the overall outcomes of the recall screening appointments when sufficient number of patients cases' have been analysed to allow for robust conclusions to be made – the analysis of this data is being actively considered and will take some time to complete.

8. Please provide a copy of the Royal College of Physicians recommendations/report (preferably in PDF format) provided to you by the RCP (please redact all personal information from this report when you provide it).

The Trust upholds its decision not to release the information requested citing the same exemption/s as detailed in our previous response.

I can confirm that an Internal Review has now taken place and our original decision to exempt the RCP Report from release under Section 40(2) of the Freedom of Information Act 2000 has been upheld. This is an Absolute Exemption and not subject to a Public Interest Test.

It is public knowledge that the Report refers specifically to Dr Watt. For this reason we would not be in a position to redact any part of the Report in order to release it to the public. This is because it is clear that the Report relates directly to Dr Watt. This is deemed to be sensitive personal information about another individual and disclosure would breach one or more of the principles of the Data Protection Act:

Principle 1 Processing Fairly and Lawfully Schedule 2 Condition 1 where consent would be required

And for sensitive personal information
Schedule 3 Condition 1 where explicit consent would be required
Section 10 – The right to prevent processing likely to cause damage or distress

Additionally, because the Report contains personal information relating to the doctor, and since disclosure to yourself is not necessary to fulfil public interest considerations such as the need to ensure appropriate action in relation to current patients, the Trust is not in a position to provide the Royal College of Physicians Report to you at this time.

Should you still be dissatisfied with the outcome, you can proceed to the second review stage by contacting the Information Commissioner, The Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, SK9 5AF who will undertake an independent review. It is important to note that if you refer any matter to the Information Commissioner, you will need to show evidence of having gone through the Trust's review process to try to resolve the matter with the Trust in the first instance.

If you have any queries regarding this letter please do not hesitate to contact me.

Yours sincerely

From: Sent: To: Subject:	02 May 2018 13:05 PublicLiaison1-SM Freedom of Information request - Multiple sclerosis and Dr Michael Watt					
Follow Up Flag: Flag Status:	Follow up Flagged					
Dear Belfast Health and Social Care Trust (Northern Ireland),						
How many patients with Multiple neuological patients at the trust?	e sclerosis did Dr Michael Watt have on his HSC list before he stopped treating					
Yours faithfully,						
Please use this email address for all replies to this request: Is publicliaison@belfasttrust.hscni.net the wrong address for Freedom of Information requests to Belfast Health and Social Care Trust (Northern Ireland)? If so, please contact us using this form: https://www.whatdotheyknow.com/change_request/new?body=belfast_health_and_social_care_trust_northern_ireland Disclaimer: This message and any reply that you make will be published on the internet. Our privacy and copyright policies: https://www.whatdotheyknow.com/help/officers For more detailed guidance on safely disclosing information, read the latest advice from the ICO: https://www.whatdotheyknow.com/help/ico-guidance-for-authorities Please note that in some cases publication of requests and responses will be delayed. If you find this service useful as an FOI officer, please ask your web manager to link to us from your organisation's FOI page.						



T: (028) 9504 5888 E: publicliaison@belfasttrust.hscni.net

1 June 2018

OUR REF: FOI/17953

Dear

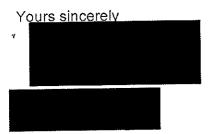
FOI ENQUIRY RE: HOW MANY PATIENTS WITH MULTIPLE SCLEROSIS DID DR MICHAEL WATT HAVE ON HIS HSC LIST BEFORE HE STOPPED TREATING NEUOLOGICAL PATIENTS AT THE TRUST?

I refer to your Freedom of Information (FOI) request received on 2 May 2018. Please find below the details you requested which I hope is helpful to you.

Dr Watt had 681 patients identified as having MS on his HSC list before he stopped treating patients at the trust.

If you are dissatisfied with the way in which your Freedom of Information (FOI) request has been handled you may wish to complain. You should contact Nore Villa, Knockbracken Health Care Park, Saintfield Road, Belfast BT8 8BH or alternatively e-mail: within two months of the date of this response and your complaint will be considered and a response provided usually within 20 working days of receipt.

Should you still be dissatisfied with the outcome, you can proceed to the second review stage by contacting the Information Commissioner, The Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, SK9 5AF who will undertake an independent review. It is important to note that if you refer any matter to the Information Commissioner, you will need to show evidence of having gone through the Trust's review process to try to resolve the matter with the Trust in the first instance.



From: Sent: To: Subject:	15 May 2018 10:19 PublicLiaison1-SM Freedom of Information request - Guidance on investigations
Follow Up Flag: Flag Status:	Follow up Flagged
Dear Belfast Health and Social Ca	re Trust (Northern Ireland),
Review Appointments-DR Watt.	
Neuralogist's for the patients th	peing reviewed by the Trust, what is the Trust's guidance to Consultant ey review who refuse to have an invasive procedure or further investigations nt with a Consultant Neurologist.
Yours faithfully,	
Social Care Trust (Northern Irela https://www.whatdotheyknow.eland Disclaimer: This message and ar policies: https://www.whatdotheyknow For more detailed guidance on https://www.whatdotheyknow	cni.net the wrong address for Freedom of Information requests to Belfast Health and and and)? If so, please contact us using this form: com/change_request/new?body=belfast_health_and_social_care_trust_northern_in ny reply that you make will be published on the internet. Our privacy and copyright .com/help/officers safely disclosing information, read the latest advice from the ICO: .com/help/ico-guidance-for-authorities
Please note that in some cases If you find this service useful as FOI page.	publication of requests and responses will be delayed. an FOI officer, please ask your web manager to link to us from your organisation's



T: (028) 9504 5888 F: (028) 9056 5553 E: publicliaison@belfasttrust.hscni.net

8 June 2018

OUR REF: FOI/18014

Dear

FOI ENQUIRY RE: WHAT IS THE TRUST'S GUIDANCE TO CONSULTANT NEUROLOGIST'S FOR THE PATIENTS THEY REVIEW WHO REFUSE TO HAVE AN INVASIVE PROCEDURE OR FURTHER INVESTIGATIONS FOLLOWING THEIR INITIAL APPOINTMENT WITH A CONSULTANT NEUROLOGIST

I refer to your Freedom of Information (FOI) request received on 15 May 2018.

Invasive procedures or investigations are not undertaken without the patient's consent. If patients indicate to their Consultant Neurologist that they do not wish to have treatment or investigations carried out, this is respected.

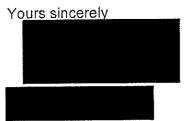
If you are dissatisfied with the way in which your Freedom of Information (FOI) request has been handled you may wish to complain. You should contact

Nore Villa, Knockbracken Health

Care Park, Saintfield Road, Belfast BT8 8BH or alternatively e-mail:

within two months of the date of this response and your complaint will be considered and a response provided usually within 20 working days of receipt.

Should you still be dissatisfied with the outcome, you can proceed to the second review stage by contacting the Information Commissioner, The Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, SK9 5AF who will undertake an independent review. It is important to note that if you refer any matter to the Information Commissioner, you will need to show evidence of having gone through the Trust's review process to try to resolve the matter with the Trust in the first instance.



From:

Sent: To: 18 May 2018 17:02 PublicLiaison1-SM

Follow Up Flag:

Flag Status:

Follow up Flagged

Dear Sir Madam

My wife is a patient of Michael Watt

Can I have access to the RCP report which you hold into a review of neurology patients under FOI. Please note the public interest test in favour of disclosure.

thanks



T: (028) 9504 5888 F: (028) 9056 5553 E: publicliaison@belfasttrust.hscni.net

7 June 2018

OUR REF: FOI/18060

Dear

FOI ENQUIRY RE: ACCESS TO THE RCP REPORT INTO A REVIEW OF NEUROLOGY PATIENTS UNDER FOI.

I write to acknowledge receipt of your FOI request received on 21 May for all or part of the Report recently received by the Belfast Trust from the Royal College of Physicians (RCP). As you will know, the Report relates to the practice of one Consultant Neurologist at the Trust, Dr Michael Watt. The full Report has been shared in confidence with Dr Watt, the Public Health Agency (PHA), the Department of Health (DoH) and the General Medical Council.

In accordance with the Freedom of Information Act 2000 we cannot fulfill your request under Section 40(2) — Personal Information Relating to a Third Party. This is deemed to be sensitive personal information about another individual. Disclosure would breach one or more of the principles of the Data Protection Act:

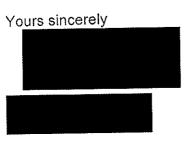
The recommendations and conclusions in the Report were shared in confidence with the Ulster Independent Clinic and Hillsborough Private Clinic, the clinics where Dr Watt was practising at the time restrictions were put in place. This was so that those organisations could ensure appropriate action in relation to those patients within Dr Watt's practice at the time of the restrictions.

While the Belfast Trust are arranging a recall of Dr Watt's current patients, and the UIC and HPC may be doing similarly, the Trust has not yet agreed with the PHA and RCP the action which may need to be taken in relation to patients who have been discharged. At present, where there are concerns from discharged patients, we are asking that these patients first speak with their General Practitioner, who can then (as required) contact the Trust on a dedicated telephone line.

The report contains personal information relating to the doctor, whose identity is known. Since disclosure to yourself is not necessary to fulfil public interest considerations such as the need to ensure appropriate action in relation to current patients, the Trust is not in a position to provide the RCP report to you at this time.

If you are dissatisfied with the way in which your Freedom of Information (FOI) request has been handled you may wish to complain. You should contact Nore Villa, Knockbracken Health Care Park, Saintfield Road, Belfast BT8 8BH or alternatively e-mail: within two months of the date of this response and your complaint will be considered and a response provided usually within 20 working days of receipt.

Should you still be dissatisfied with the outcome, you can proceed to the second review stage by contacting the Information Commissioner, The Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, SK9 5AF who will undertake an independent review. It is important to note that if you refer any matter to the Information Commissioner, you will need to show evidence of having gone through the Trust's review process to try to resolve the matter with the Trust in the first instance.



PublicLiaison-SM	
From: Sent: To: Subject: Attachments:	07 June 2018 17:02 PublicLiaison1-SM Re: 18060 - FOI Enquiry image013.jpg.htm; image018.png.htm
Follow Up Flag: Flag Status:	Follow up Flagged
Categories:	Green Category
Dear	
Thank you for your re	esponse re the Royal College Report.
My wife is a patient of	of Dr Watt and there a compelling public interest in advising her as to what the problem nation from Belfast Trust is appalling. The Trust seem very keen to apologise but to what they are apologising for. This has greatly troubled my wife.
	r Watt's personal information by redacting this. Can you confirm if you have considered like to appeal your decision. We will press the matter to the Information Commissione
Sent from my iPad	
On 7 Jun 2018, at 16	5:43, PublicLiaison-SM < publicliaison@belfasttrust.hscni.net> wrote:
Please see att	ached Trust response to your FOI Enquiry.
Apologies for	the delay in responding.
Many thanks.	
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Corporate Con	nmunication Nore Villa Knockbracken Healthcare Park Saintfield Road Belfast BT8 8BH
<image014.jr <image015.jr <image016.jr< td=""><td>pg></td></image016.jr<></image015.jr </image014.jr 	pg>

From: Sent: 18 May 2018 17:02

<image017.jpg>

<image018.png>

To: PublicLiaison-SM

Subject:

Dear Sir Madam

My wife is a patient of MIchael Watt

Can I have access to the RCP report which you hold into a review of neurology patients under FOI. Please note the public interest test in favour of disclosure.

thanks

This message contains information from Belfast Health And Social Care Trust which may be privileged and confidential. If you believe you are not the intended recipient any disclosure, distribution or use of the contents is prohibited. If you have received this message in error please notify the sender immediately.

This email has been scanned for the presence of computer viruses.

<Datix Email msg (PDF).pdf>



T: (028) 9504 5888 E: publicliaison@belfasttrust.hscni.net

3 July 2018

OUR REF: FOI/18060



Dear

INTERNAL REVIEW

FOI ENQUIRY RE: ACCESS TO THE RCP REPORT INTO A REVIEW OF NEUROLOGY PATIENTS UNDER FOI

I refer to your email dated 8 June 2018 seeking an Internal Review into our response to the above Freedom of Information (FOI) request.

I can confirm that an Internal Review has now taken place and our original decision to exempt the RCP Report from release under Section 40(2) of the Freedom of Information Act 2000 has been upheld. This is an Absolute Exemption and not subject to a Public Interest Test.

It is public knowledge that the Report refers specifically to Dr Watt. For this reason we would not be in a position to redact any part of the Report in order to release it to the public. This is because it is clear that the Report relates directly to Dr Watt. This is deemed to be sensitive personal information about another individual and disclosure would breach one or more of the principles of the Data Protection Act:

Principle 1 Processing Fairly and Lawfully Schedule 2 Condition 1 where consent would be required

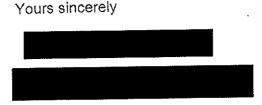
And for sensitive personal information
Schedule 3 Condition 1 where explicit consent would be required
Section 10 – The right to prevent processing likely to cause damage or distress

Additionally, because the Report contains personal information relating to the doctor, and since disclosure to yourself is not necessary to fulfil public interest considerations such as the need to ensure appropriate action in relation to current

patients, the Trust is not in a position to provide the Royal College of Physicians Report to you at this time.

We understand how difficult it is for patients and their families who have been recalled and for that we are truly sorry. The trust is doing everything possible to ensure patients are seen as quickly as possible and that any investigations which may be required are carried out in a timely way. In addition to raising any concerns at the clinic, the Trust's advice line remains open for anyone to ring. The number is: 0800 980 1100

Should you still be dissatisfied with the outcome, you can proceed to the second review stage by contacting the Information Commissioner, The Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, SK9 5AF who will undertake an independent review. It is important to note that if you refer any matter to the Information Commissioner, you will need to show evidence of having gone through the Trust's review process to try to resolve the matter with the Trust in the first instance.



Raising awareness of cerebrospinal fluid leaks

Ask for: David Baldwin

avid.baldwin@csfleak.info

PO Box 5761, Strathpeffer, IV15 0AQ, Scotland



Public Liaison Belfast HSC Trust 1st Floor, Nore Villa Knockbracken Healthcare Park Belfast Northern Ireland BT8 8BH

publicliaison@belfasttrust.hscni.net

Our Ref.: HSCB/02/FO1

Your Ref.: n/a

18 June 2018

Dear Sir/Madam,

FREEDOM OF INFORMATION ACT 2000 SPINAL CEREBROSPINAL FLUID (CSF) LEAKS, INTRACRANIAL HYPOTENSION & EPIDURAL BLOOD PATCHING

The CSF Leak Association is a Scottish Charitable Incorporated Organisation and registered charity working across the United Kingdom to raise awareness of cerebrospinal fluid (CSF) leaks. Amongst other key objectives, our charity works to improve access to the best possible standards of care and support for sufferers, and to secure clear and consistent treatment pathways within the UK's four health services.

We are aware of an on-going review and recall of 2,500 neurological cases in Northern Ireland and that some of these reviews relate to patients with CSF leaks and/or patients who have undergone epidural blood patch procedures in response to suspected CSF leaks. We are aware that as part of a separate review, the General Medical Council (GMC) has applied a number of conditions to the licence of the doctor whose cases are being reviewed.

One of those conditions states:

"6 He must only perform epidural blood patching in line with his employing trust's protocol, and his practice must be subject to regular clinical audit, at intervals agreed with his supervisor."

On behalf of the CSF Leak Association, I therefore request the following information from HSC in Northern Ireland:

- South and the second of the se
- gg perfectables concess office modified and
 - The third is the a product of the state of the control of the cont

Copposite According to a control of control of the control of the

- Copies of any and all protocols, procedural guidance and/or general guidance (whether or not they are draft, interim or adopted) relating to epidural blood patching and/or surgical glue patching in HSC in Northern Ireland. The period of interest is a ten year period up until and including the date of this letter.
- All information, in whatever format, relating to the development and/or adoption and/or review of any and all protocols, procedural guidance and/or general guidance for epidural blood patching and/or surgical glue patching in HSC in Northern Ireland. The period of interest is a ten year period up until and including the date of this letter.
- Copies of any and all protocols, procedural guidance, treatment pathways and/or general guidance (whether
 or not they are draft, interim or adopted) relating to the diagnosis, treatment and/or management of spinal
 cerebrospinal fluid (CSF) leaks and/or intracranial hypotension by HSC in Northern Ireland. The period of
 interest is a ten year period up until and including the date of this letter.
- The total number of patients diagnosed as suffering, or likely to be suffering from a spinal CSF leak and/or intracranial hypotension (incl. traumatic, latrogenic and spontaneous CSF leaks) by HSC in Northern Ireland over a ten year period up until and including the date of this letter. If this information is not available, we would ask for clarification as to how such cases are coded and recorded and, going forward, how they will be coded and recorded.
- The total number of epidural blood patches and surgical glue patches performed by HSC in Northern Ireland over a ten year period up until and including the date of this letter. If this information is not available, we would ask for clarification as to how such procedures are coded and recorded and, going forward, how they will be coded and recorded.
- Confirmation as to the availability or otherwise of the following spinal CSF leak diagnostic techniques within HSC in Northern Ireland and, if available, the institutions where they are performed:
 - a) MRI T2 STIR Sequences using Axial and Sagittal planes:
 - b) MR Myelography (Non-intrathecal gadolinium enhanced)
 - c) MR Myelography (Intrathecal gadolinium-enhanced)
 - d) CT Myelography
 - e) Dynamic CT Myelography
 - f) Digital Subtraction Myelography
 - g) Radionuclide Cisternography
 - h) Single-photon emission computed tomography (SPECT)

We do not wish to comment on the review or recall of patients itself and it is understandably and rightly a matter for the authorities involved, however we have been contacted by a number of former and current CSF leak/Spontaneous intracranial Hypotension (SIH) patients in Northern Ireland who are concerned about the adverse impact that ongoing proceedings may potentially have on their care and the treatment options afforded to them.

As an organisation focused on CSF leaks and working with experts within the NHS to secure clear and consistent diagnosis and treatment thereof, we seek your reassurance that those patients in Northern Ireland who require diagnostics and/or treatment for proven or suspected spinal CSF leaks will receive all necessary scans, tests and treatment timeously.

We would like to conclude this letter with the following general observations on spinal CSF leaks and intracranial hypotension:

 It has been demonstrated that many spinal leaks do not show on MR imaging¹ and evidence of resultant intracranial hypotension can be absent in up to 20% of cases²; basing firm diagnosis upon imaging alone (including ruling out a CSF leak) or finding the location of a leak can be an enormous challenge for doctors.

Kranz, PG et al. 2018 "Spontaneous intracranial Hypotension: 10 Myths and Misperceptions" https://onlinelibrary.wilev.com/doi/epdf/10.1111/head.13328
Schlevink, Wt. 2006 "Spontaneous Spinal Cereprospinal Fluid Leaks and Intracranial Hypotension" https://jamanetwork.com/journals/jama/fullariticle/202849

- 2. Imaging Signs in Spontaneous Intracranial Hypotension: Prevalence and Relationship to CSF Pressure, published by Kranz et al in 20163, notes that of 93 subjects in their study 17% showed no abnormal dural enhancement; 39% showed no evidence of brain sagging, and; 25% showed no venous distension sign, concluding that there is weak correlation between individual brain or myelographic imaging signs and a patient's CSF pressure.
- 3. Spontaneous cerebrospinal fluid leaks: from intracranial hypotension to cerebrospinal fluid hypovolemia evolution of a concept, published by Mokri in 1999, notes serveral modes of presentation for spontaneous intracranial hypotension, including: a) those where clinical-imaging is normal and CSF pressures consistently within normal limits, and b) cases with an absence of diffuse pachymeningeal gadolinium enhancement with presence of low CSF pressures and typical clinical manifestations.
- 4. A lumbar puncture may be performed to measure CSF pressure, but is not required to make a diagnosis and readings within 'normal range' are not uncommon despite a leak being present'; one recent study noted low readings in only 34% of subjects with a spinal CSF leak⁶, while another demonstrated low pressure in only 55.3%⁷.
- 5. There are still few SIH experts globally let alone within the UK, and a belief that the condition is defined by the presence of low CSF pressure, while still common, is no longer sufficient or accurate⁸. Studies show that familiarity with the spectrum of presentations and causes of SIH is critical to accurate and timely diagnosis and management9..
- 6. Leading experts have noted that unfamiliarity with the condition among medical professionals in general, along with the unusually varied spectrum of clinical and radiographic manifestations, can and does lead to misdiagnosis and/or diagnosis delay spanning months and years 1011
- 7. While no surgical procedure is risk-free and some uncommon complications (mainly temporary) are noted12, epidural blood patching is generally considered to be relatively low risk, safe and effective 1314. The seminal "Diagnostic Criteria for Spontaneous Spinal CSF Leaks and Intracranial Hypotension", published in 200815, also notes the use of epidural blood patching as a diagnostic tool, as well as a treatment option.

If some or all of the information requested is not held by yourselves, rather it is held or likely to b held by other organisations within HSC in Northern Ireland, I would appreciate it greatly if you would either forward this request to them or provide contact details to me by return so that we may forward it ourselves.

I look forward to hearing from you in due course. If, however, you require clarification or any further information from me, please do not hesitate to contact me using one or more of the methods above.

David Baldwin Chairman

For and on behalf of the CSF Leak Association

Kranz, PG. 2017 "Imaging Signs in Spontaneous Intracranial Hypotension: Prevalence and Relationship to CSF Pressure" http://www.ajor.org/content/37/7/1374

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¹¹ Kranz, PG et al. 2018 "Spontaneous Intracranial Hypotension: 10 Myths and Misperceptions" https://onlinelbrary.wiley.com/doi/epdf/10.1111/head.13328
12 Sorour, M. 2014 "Intraventricular Hemorrhage after Epidural Blood Parching: An Unusual Complication" https://www.hindawi.com/journals/crinm/2014/406289

¹³ Kalina, P. 2016 "A complication of an epidural blood patch" https://www.jocn-lournal.com/article/50067-5868[16]30233-8/fuiltext

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8 August 2018

Our ref: FOI/18248

David Baldwin CSF Leak Association PO Box 5761 Strathpeffer IV15 0AQ

Dear Mr Baldwin

RE: Spinal Cerebrospinal Fluid (CSF) Leaks

I refer to your Freedom of Information (FOI) request received 20 June 2018. Please find attached the details you requested. I hope this information is helpful.

If you are dissatisfied with the way in which your Freedom of Information (FOI) request has been handled you may wish to complain. You should contact Nore Villa, Knockbracken Health Care Park, Saintfield Road, Belfast BT8 8BH or alternatively e-mail:

within two months of the date of this response and your complaint will be considered and a response provided usually within 20 working days of receipt.

Should you still be dissatisfied with the outcome, you can proceed to the second review stage by contacting the Information Commissioner, The Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, SK9 5AF who will undertake an independent review. It is important to note that if you refer any matter to the Information Commissioner, you will need to show evidence of having gone through the Trust's review process to try to resolve the matter with the Trust in the first instance.

Yours sir	cerely		