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"Fw: vCJD post-mortem tissue survey"

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06/08/2011 08:04	Refiled from GHP/008/022/002 to GHP/008/022/002 Vol 9

Ailsa Wight/PH6/DOH/GB
04/11/2009 19:26

To Ben Cole/HP-SL/DOH/GB@GRO-C
cc Mark Noterman/CQEG/DOH/GB@GRO-C
bcc
Subject Fw: vCJD post-mortem tissue survey

Has anything happened about this?

Dr Ailsa Wight
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----- Forwarded by Ailsa Wight/PH6/DOH/GB on 04/11/2009 19:24 -----

"Benbow Emyr \(RW3\) CMFT Manchester" <Emyr.Benbow@ GRO-C
GRO-C
30/09/2009 09:21

To Ailsa Wight/PH6/DOH/GB@GRO-C
cc
Subject RE: vCJD post-mortem tissue survey

Might be worth involving Neil Shepherd and John McCarthy, the lead histopathologists for that pilot, too.

Emyr

Dr Emyr W Benbow BSc MB ChB FRCPath
Senior Lecturer in Pathology, University of Manchester
Consultant Pathologist, Manchester Royal Infirmary
GRO-C

From: Ailsa.Wight@ GRO-C [mailto:Ailsa.Wight@ GRO-C]
Sent: 30 September 2009 08:42
To: Benbow Emyr (RW3) CMFT Manchester; Mark.Noterman@ GRO-C
Cc: Noel Gill; Carole Kelly; Helen Janecek; Simon Bennett
Subject: Re: vCJD post-mortem tissue survey

That is a pity. We had a discussion with the DH 'examiner' lead (Simon Bennett) who thought it would be worth involving him. Simon also mentioned a pilot in Gloucestershire and we plan to approach the lead coroner there too.

Message sent from a Blackberry handheld device.

----- Original Message -----
From: "Benbow Emyr \(RW3\) CMFT Manchester" [Emyr.Benbow@ GRO-C
Sent: 30/09/2009 08:10 CET
To: Ailsa Wight; Mark Noterman
Cc: Noel Gill" <Noel.Gill@ GRO-C >; Carole Kelly" <Carole.Kelly@ GRO-C >; Helen Janecek" <Helen.Janecek@ GRO-C ; Jonathan Clewley" <Jonathan.Clewley@ GRO-C >
Subject: RE: vCJD post-mortem tissue survey

Chris Dorries, the Coroner for Sheffield, is one of my co-editors on a project for the DoH, and we met yesterday. I mentioned the possibility of a further pilot in Sheffield, and he isn't at all interested. Not in the slightest!

Emyr

Dr Emyr W Benbow BSc MB ChB FRCPath
Senior Lecturer in Pathology, University of Manchester
Consultant Pathologist, Manchester Royal Infirmary
GRO-C

From: Benbow Emyr (RW3) CMFT Manchester
Sent: 22 September 2009 15:38
To: 'Jonathan Clewley'
Cc: Noel Gill; Carole Kelly; Helen Janecek
Subject: RE: vCJD post-mortem tissue survey

Hi Jonathan

First, some answers to your specific questions:

Do you consider, in light of the recent finding of abnormal prion protein in the spleen of a patient with haemophilia at post-mortem, that spleen samples are taken from the capsular region of the spleen? Also, do you agree or not that it might be wise to take a larger sample from the spleen (for example, 2 cm3) so that repeat tests may be carried out.

Pathologists taking samples of solid organs for histological sections will take blocks of about 2cm x 2cm x 0.3cm, and when taking blocks of spleen, many will favour a block with capsule running along the narrow edge just to hold this rather soft material intact. Given that the normal spleen has a volume of 150 to 200ml, there's no reason why you shouldn't ask for samples of the volume you describe, or even more.

For the brain samples, is there any particular region of the frontal cortex that is preferable?

I'm not a neuropathologist, so you might want to ask James Ironside this question. However, I can find nothing in the literature that suggests any site of prediliction within the frontal cortex. vCJD causes its morst prominent changes in and around the thalami, so I can't quite work out why you prefer the frontal cortex, though the tissue there is more uniform.

What size sample would you recommend being removed from the brain?

How much do you need? Given that the brain is a large organ, there's no reason why you shouldn't request quantities comparable to those from the spleen. Perhaps I could answer this with greater precision if you told me what your ideal sample would be.

Are there any other changes to the protocol wording above that you would suggest, given that it is to be read primarily by the APT, but also by the pathologist?
I think that most of my concerns were aired adequately last Thursday, but I have a two more suggestions:

Page 4, first bullet points: take out the phrase "for the purpose of determining the cause of death" because it tends to exclude the hospital consent autopsy.

Page 6, para 1: tissue samples are taken by the pathologist, not the APT, thouguh the APT will then be responsible for labelling and forwarding.

And now some more gerenal observations:

I'm also still concerned about the idea that, when families change their mind about allowing testing, then the only option is disposal. I was speaking at a confernence on Saturday, and one of the HTA's Inspectors was also speaking, and I outlined my concerns. She shares my surprise at the outcome that Helen described, and I think that this need clarificaiton with the HTA. In the HTAct, retention without consent is a crime; disposal without consent is not, so you would not be breaking the law. However, disposal without the option of return would be against the spirit of the law. More importantly from your point of view, pathologists reading the protocol would pick up on this discrepancy, and would be very concerned that to assit you would make them vunerable to criticism by the HTA. Am I allowed to know who wrote to Helen, from the HTA, to approve this procedure?

The President of the RCPath took a harder line than mine over the issue of support from the RCPath, and is very keen to have confirmation of the scientific value of the project: I'd therefore like to know about the respopnse of SEAC to your request for justification. Further, I don't think you'd get RCPath support until you sort out the HTA issue in the last paragraph.

And just one final thing: givne that you are establishing an archive of material for "future research" (page 1, bullet point 4), are you aware that this changes the status of the material under the HTAct, and that you will need a license to store the material? Establishing an archive is different to keeping tissue for a one-off project.

Emyr

Dr Emyr W Benbow BSc MB ChB FRCPath
Senior Lecturer in Pathology, University of Manchester

Consultant Pathologist, Manchester Royal Infirmary
GRO-C

From: Jonathan Clewley [mailto:Jonathan.Clewley@ GRO-C]
Sent: 21 September 2009 09:47
To: Benbow Emyr (RW3) CMFT Manchester
Cc: Noel Gill; Carole Kelly; Helen Janecek
Subject: vCJD post-mortem tissue survey

Dear Dr Benbow

Thank you for your contributions to last week's meeting on vCJD Post Mortem Prevalence Studies at the Department of Health. If possible, we'd be grateful for your further advice on the issues involving collection of spleen and brain samples for the Pilot Study that is due to begin shortly.

In the protocol, it currently states that:

"The Survey Record will indicate to the receiving pathologist and APT if consent for spleen removal (or spleen sampling) only, or for spleen removal (or spleen sampling) and brain tissue sampling, has been obtained. Once the pathologist is satisfied with the examination and decides that no further spleen and brain (if appropriate) tissues are required for the purpose of establishing the cause of death, and, where appropriate, that the coroner's function will not be affected by removal of tissue for the survey, the APT or the pathologist will collect the specimen(s). They will remove: either the whole spleen or two samples of spleen measuring about 1 cm3 (approximately the size of two sugar lumps) from the capsular region of the spleen, avoiding any areas of the organ obviously severely affected by a disease process and, provided consent has been given for brain sampling, and that the organ is examined as part of the autopsy and accessible for sampling, two samples of brain tissue measuring about 1 cm3. The samples should be obtained from the frontal cortex if possible but, if this part of the brain is affected by a disease process in such a way that sampling of this region is unsuitable, then another part of the organ may be sampled."

Do you consider, in light of the recent finding of abnormal prion protein in the spleen of a patient with haemophilia at post-mortem, that spleen samples are taken from the capsular region of the spleen? Also, do you agree or not that it might be wise to take a larger sample from the spleen (for example, 2 cm3) so that repeat tests may be carried out.

For the brain samples, is there any particular region of the frontal cortex that is preferable? What size sample would you recommend being removed from the brain?

Are there any other changes to the protocol wording above that you would suggest, given that it is to be read primarily by the APT, but also by the pathologist?

Your comments and recommendations would be greatly appreciated.

Many thanks, sincerely

Jon

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