

**NATIONAL ACUTE PORPHYRIA SERVICE**

**Purpose of briefing**

This briefing explains what is happening to the National Acute Porphyria Service (NAPS) now that it is no longer being delivered at Cambridge University Hospitals NHS Foundation Trust (Addenbrooke’s Hospital).

**July 2014**

During July 2014, Dr Penny Stein (whose contact details remain the same) will continue to look after the following groups of patients on an interim basis:

* Patients who receive haem arginate through a homecare arrangement (regardless of whether or not they are a patient at Addenbrooke’s)
* Patients with appointments already booked at Addenbrooke’s
* Other current Addenbrooke's patients who have a problem related to their porphyria, such as a hospital admission with an attack

The arrangement for hospitals to be directly supplied with haem arginate will continue via the pharmacy at Addenbrooke’s for three months or until an alternative arrangement has been put into place (whichever is the sooner).

The on-call NAPS service will continue to be available during July 2014 on the usual number (02920 747747), with the centres in Cardiff and King’s College Hospital, London responding to queries.

**August to October 2014**

Dr Stein will work on an interim basis from King’s College Hospital, London, looking after the following groups of patients:

* Patients who choose to transfer from Addenbrooke's to King's
* Patients who receive haem arginate through a homecare arrangement
* Patients who are usually seen at the outreach clinic in Leeds with Dr Julian Barth (and who will continue to be seen at the outreach clinic in Leeds by Dr Stein and Dr Barth)

Other outreach arrangements may be put into place during this period for patients who would find travel to King’s College Hospital difficult.

Dr Stein will have new contact details, which we will let you have once they are finalised. These details will include the dedicated times each day when she will be available to respond to queries.

**Transfer of care**

Patients are being given a choice as to whether they would like their care transferred to Cardiff or King’s Hospital, London. It is essential that patients make a choice so that their records are transferred to a team that has expertise in looking after patients with acute porphyria.

Where patients have already chosen Cardiff, their records will be transferred to Cardiff, together with a summary care plan prepared by Dr Stein. Where patients have already chosen King’s Hospital, London, their records will be transferred to King’s Hospital, again with a summary care plan prepared by Dr Stein. Patients who have already made a choice and have changed their mind should contact Addenbrooke’s as soon as possible.

Where a patient has not made a choice, we strongly recommend that they agree for their records to be transferred to King’s College Hospital so that Dr Stein may access their records whilst she is employed there on an interim basis. **The British Porphyria Association supports this recommendation.** Patients will be able to make a further choice in the future, depending on the outcome of the decision on the future of the NAPS as described below.

**Homecare arrangements**

NHS England is working with Bupa – the company that runs the homecare arrangements for haem arginate – to ensure that patients’ needs continue to be met by this service.

**The future of NAPS**

NHS England is exploring options about how the porphyria service should be delivered in the future. One option is to focus the service at King’s College Hospital, London and Cardiff), which would build further expertise and resilience at these two expert centres. A second option is to secure an alternative third centre to replace Cambridge. For both options, it will be important to take into account the geographical location of the existing centres and the need to ensure equitable access to patients regardless of where they live. This might for example include delivering more of the service through outreach arrangements.

If NHS England chooses to pursue the establishment of an alternative third centre, this would need to be secured through open competition across the UK. A process would be put in place to ensure that the centre chosen was able to deliver a service that not only met the standards set out in the service specification (this is the document that NHS England uses to make sure that hospitals deliver a service that meets the specific needs of patients with acute porphyria) but was able to demonstrate that they could deliver equitable access to patients.

**How NHS England will decide about the future of NAPS**

It is very important that patients and their families give their views about the future of the NAPS. We plan to do this in four stages:

1. Contact patients via the centres (due to patient confidentiality) to find out what they liked about the service at Cambridge and whether there was anything that could be improved.
2. Take all the information given to us and develop some options; we will need to make sure that these options are viable and will need to test them with the expert clinicians that deliver the service
3. Ask patients and their families to consider the options
4. Implement the most favoured option

If you have any questions about this briefing, please contact Fiona Marley: [Fiona.marley@nhs.net](mailto:Fiona.marley@nhs.net)

Telephone: 07795 636 830.

**Contact details for the two expert centres in case patient wish to discuss their care before making a choice:**

**London Porphyria Service**  
Department of Haematological Medicine  
King’s College Hospital NHS Foundation Trust  
Denmark Hill  
SE5 9RS  
Lead clinician: Dr. David Rees

e-mail address: david.rees2@nhs.net  
Tel: 0203 299 4181 (secretary)

<http://www.kch.nhs.uk/Doc/pl%20-%20545.1%20-%20porphyria%20clinic.pdf>

**Cardiff Porphyria Service**  
Department of Medical  
Biochemistry & Immunology  
University Hospital of Wales  
Heath Park  
CF14 4XW  
Lead clinician: Dr. Mike Badminton,

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