FREEDOM OF INFORMATION – CHRONIC FATIGUE CLINIC

I write in response to your request of 6 June 2007 (received 8 June 2007) for information on the Regional Infectious Diseases Unit (RIDU) and particularly the Chronic Fatigue Clinic (CFC).

I have been provided with information to answer your request by Mrs Sue Donaldson (Clinical Nurse Manager Metabolic Unit, Western General Hospital) :-

- **Who runs the Infectious Diseases Unit?**

  The unit is part of the Medical division of the University Hospitals Division (UHD), an operating division of NHS Lothian. The Infectious diseases/genitourinary medicine directorate incorporates RIDU and the GUM department at Lauriston Place. The Clinical Director of ID/GUM is Dr Gordon Scott (based at GUM). Dr Wilks is professional lead for Infectious Disease, based at RIDU, the Western General Hospital.

- **Who runs the chronic fatigue clinic? Is it a one-doctor situation?**

  Dr Wilks has been doing a dedicated Chronic Fatigue Syndrome (CFS) clinic for the past 12 years, and is the consultant with most interest in this area. Recently Dr Mike Jones started to do a similar clinic session. Other consultants in the department also receive referrals from GPs for patients with fatigue, and these patients are usually seen in general Infectious Disease (ID) clinics. Dr Wilks is the unit’s representative on the Lothian CFS/ME Managed Clinical Network Development Group, and is also centre co-leader for the PACE trial (see below).

- **What is the status of the clinic?**

  The ID Unit has had a longstanding interest in unexplained fatigue (stemming originally from the observation that many patients with unexplained fatigue initially become unwell after an apparent viral infection i.e. “post-viral fatigue”). Patients with fatigue have been referred by
GPs to the unit for over 20 years, although over time individual consultants have varied in their approach. Some offered assessment followed by advice, often about exercise and/or lifestyle modification and then discharged the patient - others offered continued follow-up although this became more difficult to sustain as workload from other conditions such as HIV increased.

The clinic was not designated as “The Chronic Fatigue Clinic” by NHS Lothian and until recently received no specific funding for CFS – the decision to continue to see patients in this category was made by consultants within the unit because:-

- There were quite a number of patients already attending
- There was ongoing demand from GPs for help with these difficult cases
- The unit had built up expertise in assessment, and links with other services such as respiratory and general physiotherapy, which meant that they could offer an assessment service, which was apparently popular with GPs and patients.

- Does the unit receive any private funding?
  No

- Is there self-governing aspects of the Unit(?)
  The Infectious Diseases unit (& its associated clinics) is part of UHD and part of NHS Lothian. Day to day running of the unit is subject to all the management arrangements of the division, and responsibility for clinical standards is part of the clinical governance framework of UHD.

- How is it officially described?
  The chronic fatigue clinic is essentially an informal description, which indicates that consultants within the unit have experience in CFS and are willing to see patients with that condition. The chronic fatigue clinic differs from other clinics in the hospital in the following ways :-
  - Staff at the clinic have experience of CFS
  - Appointments are scheduled at one hour intervals for new patients to allow time for detailed discussion of the patient’s symptoms
  - Staff have knowledge of other professionals in Edinburgh who can be useful to patients with CFS. In particular, patients wishing to take part in the Lifestyle Management Programme funded by NHS Lothian and delivered by the Thistle Foundation in Craigmillar are assessed at RIDU to ensure that there is no other physical diagnosis that might require alternative treatment.

Continued
Does it produce information on how many patients it sees and treats for CFS and what is the success rate of treatment?

Activity figures from 19990 onwards are as follows:-

<table>
<thead>
<tr>
<th>Year</th>
<th>New Patients</th>
<th>New Appointments</th>
<th>Return Patients</th>
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<td>269</td>
<td>441</td>
</tr>
</tbody>
</table>

The clinic is an assessment service – it is not funded to provide treatment and has no resources to do so. The entire resource available to the CF clinic consists of 3 four-hour clinic slots and the associated administrative overhead.

Patients are seen for assessment with the following in mind:

- Can an alternative physical diagnosis be made, which might open the way to more specific therapy?
- Are there other factors identifiable that might be contributing to the patient’s fatigue? In this respect we try to follow a biopsychosocial model of illness which considers not just the patient’s physical and mental health, but also their previous experiences and social relationships.
- Does the patient satisfy current diagnostic criteria for CFS?
- If so, what treatments have been shown in properly conducted clinical trials to benefit patients with CFS, and would they be applicable in this particular case?
- Unfortunately there are very few treatments that have been shown in properly conducted clinical trials to be of benefit to patients with CFS. The two interventions, which have the best evidence base, are graded exercise therapy and cognitive behaviour therapy. Both of these have been shown in several trials to be of benefit – a full exploration of this matter is beyond the scope of this reply, but scientists at the University of York have published a useful systematic review, and a copy is attached.

Neither of these treatments is currently easily available to patients in Lothian. RIDU has no funds for provision of therapy. Community physiotherapy departments do not have adequate
resources to replicate the level of intensive intervention shown to be necessary for effective and safe graded exercise programmes. NHS clinical psychology services can provide Community Based Treatment, but in general have a long waiting time.

- **Is there a directive on how its budget should be spent – does it state that a certain amount should be spent on CFS?**

The ID unit provides a number of services of which the most expensive is the care of HIV+ persons. We also look after patients with community-acquired infections such as pneumonia. Until recently there was no specific budget for CFS. For about 2 years we have received £10,000 p.a. from NHS Lothian, specifically to allow us to increase the capacity of the assessment clinic.

The funding for the CFS/ME Referral Clinic was agreed by a working group, established by Lothian NHS Board. There is no “directive” to Scottish Health Boards concerning specific funding for CFS/ME services.

- **Has there been any adverse publicity surrounding the unit?**

Prior to your correspondence there had been no formal complaints received in respect of the CFS clinic at RIDU. Although the team may differ in opinion over certain aspects of the nature of CFS, it enjoys good relations with MESH, the local CFS/ME self help group, and as far as the team is aware is regarded by them as a helpful and sympathetic resource. RIDU is regarded as providing a standard of care to patients with HIV and other infectious diseases, which is as good as any in the UK and probably the world.

- **What’s the background of David Wilks?**

Dr Wilks qualified from the University of Cambridge and trained in London and Cambridge. He was appointed as a consultant in Edinburgh in 1995. He has been seeing patients with CFS since 1988 when he started to train in the speciality of Infectious Diseases. His special interests include HIV, hepatitis C, community acquired infection and chronic fatigue syndrome.

He is the author of a textbook of Infectious Diseases, and has published articles on HIV and CFS (listed).

Dr Wilks was a member of the Scottish Executive Health Department Short-Life Working Group on CFS and the Lothian Health Action Group on CFS/ME. He is a member of the Lothian CFS/ME Managed Clinical Network Development Group. He is centre co-leader for the PACE trial, which is a multi-centre MRC funded study examining a number of different therapies for CFS.
• **Anything of note here?**

Dr Wilks is regarded as a highly experienced and skilled consultant with a wealth of knowledge and who demonstrates exemplary professional conduct at all times in all settings. Clinical colleagues, patients and the Clinical Management Team would describe him as an empathic, caring and articulate consultant who always views his patients’ well being as a priority.

• **Who or what is the department answerable to? Is there any mention of how the unit is assessed for effectiveness?**

This question is already answered in part above under “self-governing aspects”. With regard to review of effectiveness, the unit has an ongoing internal programme of clinical audit examining a number of process and outcome issues. Most of these reflect activity in HIV medicine, where there are clearly defined and easily measurable outcomes. This is more difficult for CFS, which is by definition more difficult to categorise.

The unit was one of about six UK-wide that was approved by the Medical Research Council when the PACE trial was started, and has been inspected on at least two occasions by trial staff to ensure compliance with the trial protocol, which includes specific stipulation on how patients with CFS should be assessed. This guidance was developed in association with the trial principal investigators, who are regarded as UK leaders in the field, and in co-operation with the charity Action for ME, who are partners in the trial and who are represented at the Trial Management Group.

The unit has not recently carried out patient satisfaction surveys in the CFS clinic. However, it would be feasible to do this and it is the intention of the clinical team to do so.

• **Publications by Dr Wilks in the field of CFS**


Continued
Myers C. Wilks D.
Comparison of Euroqol EQ-5D and SF-36 in patients with chronic fatigue syndrome.

I hope this information helps with your request.

If you are unhappy with our response to your request, you do have the right to request us to review it. Your request should be made within 40 working days of receipt of this letter, and we will reply within 20 working days of receipt. If our decision is unchanged following a review and you remain dissatisfied with this, you then have the right to make a formal complaint to the Scottish Information Commissioner.

If you require a review of our decision to be carried out, please write to Mr I Whyte, FOI Reviewer at the address at the foot of this letter. The review will be undertaken by Mr Whyte as he was not involved in the original decision making process.

FOI responses (subject to redaction of personal information) may appear on NHS Lothian's Freedom of Information website at :- http://www.nhslothian.scot.nhs.uk/your_rights/foi/foi_09.asp.

Yours sincerely

JOHN MATHESON
Director of Finance
Cc: Chief Executive