

**BLOOD & BONE MARROW DONATION: MEETING WITH THE
NATIONAL BLOOD AUTHORITY: TUESDAY 25 JULY AT 3PM IN ROOM
LG 18 WELLINGTON HOUSE**

Present

NBS

Liz Reynolds, Director of Public & Customer Services
Dr Christina Navarrete, Head of Histocompatibility & Immunogenics
Teresa Turvey, British Bone Marrow Registry

DoH

Dr Mike McGovern, Health Services Directorate
Charles Lister, Health Services Directorate
Kamini Gadhok, Race Equality Unit

Action Points

1. Handling family campaigns

It was agreed that all requests for increasing donor collections should be made in writing to the BBMR with no action being taken until NBS had met with those involved to determine impact and plan the recruitment campaign. Numbers of samples to be collected would be agreed in advance with the family. Teams would be carefully selected where campaigns were targeted to ethnic minority groups.

NBS would work this proposal into a detailed plan, mapping out the key players, ensuring that all links were properly established and identifying a central co-ordinating point. The aim was to ensure that families were properly guided through the process and that there were no gaps.

Action: NBS

2. Impact on registry collection target

NBS calculated that, at the present increased rate of collection, new registrations could reach 20,000 in 2000/2001, costing around an additional £1m. Also, over the next 5 years, 25% of donors currently registered would fall out of the registry on age grounds. Improvements were also desirable in the quality of tissue typing. New donors on the BBMR were typed at Class 1 and Class 2. A number of existing donors had only been typed at Class 1, and there was a case for extending Class 2 typing to a number of these. There were therefore also longer-term funding implications for the registry.

NBS would look to see if the additional £1m needed in-year could be found from their existing resources. Otherwise, an approach would be made to the Department.

Action: NBS

NBS would prepare a business case for direct government funding for the registry from 2001/2002 onwards. Charles Lister agreed to check the position on bids for central funding for 2001/2002 to see if there was still time to put in a supplementary bid. [After subsequent discussion with Steve Morgan, it was agreed not to pursue this]

Action: NBS
Charles Lister

Another possible way forward was for NBS to set up a charity or trust fund to support the registry. Before the question was debated further, Charles Lister agreed to check with DH lawyers to see if this was possible.

Action: Charles Lister

3. Size/Ethnic balance of the BBMR

The three UK registries covered more than 400,000 donors. This was felt to be an acceptable size overall. However, there were questions on whether ethnic minority groups were sufficiently represented and therefore whether the service provision was equally good for all sections of the community. The NBS did not carry out routine ethnic monitoring of blood and bone marrow donors – many collection teams were embarrassed to collect such information or had concerns that it might be considered racist.

Ethnic monitoring was an issue throughout the NHS and was being addressed through staff training. It was suggested that NBS might adopt the same questions as the rest of the NHS, and should contact Greg Phillpotts in the Department's Statistics Division who ran the National Information Strategy Group which was working on this area. NBS were also considering a postal questionnaire for existing donors.

Action: NBS

Kamini Gadhok agreed to provide comments to NBS on a leaflet explaining bone marrow donation.

Action: Kamini Gadhok

4. Recruitment of blood donors from ethnic minorities

Attempts by NBS in 1999 to recruit more Asian blood donors had represented poor value for money given the low take-up. Kamini Gadhok suggested that some general background education of ethnic communities was perhaps needed. This could be undertaken by local health promotion teams and could also be used as an information gathering exercise for NBS on how best to target ethnic groups. She offered to work with NBS on setting up a pilot, focussing on one ethnic group in one part of the country.

Action: NBS
Kamini Gadhok

5. Promoting greater collaboration between the 3 UK registries

It was agreed that there was scope for greater collaboration between the 3 UK registries, particularly between the BBMR and the Anthony Nolan Trust to make best use of existing resources. Previous offers of assistance made to the Trust by NBS had not been taken up. DH would give consideration to hosting a workshop to bring the three registries together to discuss this area.

Action: DH

6. Media Handling

Given the level of local media activity around the various family campaigns, including claims that bone marrow donation in the UK is under-funded and should not be reliant on charitable donations, there was strong likelihood of a story breaking in the national media. It was agreed that NBS and DH would put together a joint media handling brief as a matter of urgency, with a first draft provided by NBS.

Action: NBS
DH