

From Norman Lamb MP  
Minister of State for Care and Support



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Mr Chris James  
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26 NOV 2012

*Dear Chris James,*

Thank you for your letter of 15 October to Jeremy Hunt about support for people with haemophilia and other bleeding disorders. I am replying as the Minister responsible for policy on long-term conditions.

I am pleased to see the Haemophilia Society's acknowledgment of the high standards of care in place in many areas for people with haemophilia and other bleeding disorders. This is a significant achievement, and reflects the hard work and dedication of both service commissioners and service providers, and valuable input from the patient community. Whilst I cannot comment on haemophilia services outside of England, which are the responsibility of the devolved administrations, I see no reason why the process of change to the NHS system in England should jeopardize services. On the contrary, the changes we are implementing should lead to better planned and better co-ordinated services that are more consistent country-wide, as they will be the subject of a single national commissioning policy.

The NHS Commissioning Board will directly commission specialised services for haemophilia, and other related bleeding disorders, from April 2013. Services will be set out in regulations, linked to a robust service specification, and supported by a commissioning manual that provides detailed information on the scope of services to be commissioned. The service specification has been finalised, and I understand that the Society was involved in that process. As you know, it will now be going through a formal signing off process, followed by a national consultation lasting four weeks.

As you say, the Society has been playing an important role in contributing to the development of haemophilia services and treatments, and I see no reason why you should not continue to be similarly involved in the development of services in future.

We have not yet had an opportunity to consider meetings between the four UK Health Departments and the Haemophilia Alliance. However, I am sure you will appreciate that once the new NHS structures are in place, the Department of Health will have no involvement in the commissioning and delivery of haemophilia services. I would expect that commissioners of services in England will have their own forum for involving haemophilia patients and their care professionals as they continue to deliver services.

Nevertheless, I am pleased that you find the meetings with officials to be constructive. Whilst I do not believe that it is necessary to have a formal arrangement to enable discussion of matters pertaining to the five ex-gratia financial assistance schemes, I would encourage you to continue to build on the positive relationship you already have with officials, and raise any specific concerns with them.

Changes to the benefits system are a matter for the Department for Work and Pensions. However, we would not want to see any change to the benefits system that adversely affects patient care.

I also note your concerns about your capacity building grant. When the previous Government awarded the Haemophilia Society a section 70 grant in 2009, it was for a period of five years to enable you to build your capacity during that time. There was no expectation given to the Society that it might continue or be renewed. The Department has a national grants scheme called the Innovation, Excellence and Strategic Development Fund, which provides funding from one to three years to support proposals in health and care. The Society is free to apply to this scheme. Details about how to do so can be found on the Department's website ([www.dh.gov.uk](http://www.dh.gov.uk)) by searching for 'IESD' and following the links.

However, I should note that the fund does not provide core funding. The available funding is very limited and to be successful, organisations will need to have a clear focus in their applications on how their proposals would support and drive forward new ideas, disseminate and replicate excellence or undertake strategic developments in voluntary sector capacity or capability in health and care. Given that your capacity building grant is coming to an end in 2014, I would suggest that you use the time between now and then to explore alternative sources of funding. Officials are prepared to work with the Society to develop

an exit strategy and to help establish what measures can be undertaken to engage with commissioners.

Finally, I would like to thank you for sharing the current draft of the Society's contaminated blood policy. I note that you intend to review it again in the light of the findings of the Penrose inquiry. We would be grateful if, after doing so, you could provide officials with a copy of the policy document so that any issues can be addressed.

I hope this reply is helpful.

*Yours Sincerely,*

GRO-C

**NORMAN LAMB**

*I am so sorry for the delay in responding.*