

The Rt Hon Matt Hancock MP
Secretary of State for Health and Social Care
Department of Health and Social Care
39 Victoria Street
London
SW1H 0EU



22 November 2018

Dear Mr Hancock,

As MPs with constituents who have haemophilia and other bleeding disorders, we are writing to urge you to put in place measures to ensure that they have priority access to the best medical treatments and healthcare support available, and to review the current tendering process for blood products in light of the development of new and better haemophilia treatments.

For many years, the APPG on Haemophilia and Contaminated Blood and others have campaigned for priority access for this community, as well as the broader group of people affected by the contaminated blood scandal. Indeed, the 2009 Archer Inquiry recommended that a statutory committee be set-up to procure 'readily available access to any necessary treatment relating to the condition itself', amongst other things (Recommendation 1a). Now that the Infected Blood Inquiry is under way, and held its first hearing on 24 September, we feel that it is imperative that the Department of Health and Social Care revisits this important recommendation and takes action to support this small community.

As part of this, we feel that there need to be changes to NHS England's processes for procuring treatment for people with haemophilia and other bleeding disorders. Treatments are now becoming available which hold the prospect of quality of life improvements for this patient group - new Extended Half Life (EHL) clotting factor products, for example, are in many cases able to reduce the frequency of injections and factor consumption, while lowering the number of spontaneous bleeds that patients experience. We also look set to see further treatments developed which may deliver unprecedented quality of life improvements for people with bleeding disorders.

These are highly significant and positive developments. However, we are concerned that the processes NHS England has in place to decide which treatments for haemophilia are made available risk preventing us from reaping the full benefits.

We have four key concerns about these processes.

Firstly, we feel that the tender process NHS England currently operates is too heavily based on cost, and neglects the wider quality of life benefits which new treatments could bring. Unlike for many other medical treatments, decisions on which bleeding disorder treatments will be made available to patients are based solely on the results of national procurement exercises run by NHS England. We understand that NHS England's approach is currently directed towards evaluating treatments based on their cost, rather than other factors such as clinical outcomes and patient experience. We do not believe that this approach is appropriate as in practice it may lead to patients facing restrictions in access to treatments that may deliver better quality of life.

Secondly, the UK compares unfavourably with other countries in terms of outcomes for patients with severe haemophilia. A recent study into the cost of severe haemophilia in Europe found that the UK spends the least and also scores the worst treatment outcomes, of any country in the EU5. There are examples of different approaches even closer to home, with Ireland having recently revised its approach towards haemophilia treatment to ensure that every eligible patient in the country is able to access EHLs. This followed a similar contaminated blood scandal, which led to a three-pronged response, delivered in parallel: an inquiry, financial compensation and priority access to medical treatments and healthcare support. It is essential that the UK Government follows a similar model: amongst other things, this means building on the historic commitment to an inquiry by making effective provision for new treatments.

Thirdly, rather than empowering patients, we feel that NHS England's approach to commissioning care imposes top-down barriers to access which limit patients' ability to receive the best care and support available. For example, it has put in place strict prescribing guidance that in effect limits eligibility for EHLs. We would welcome assurances that this guidance will be reviewed to ensure that it is not preventing appropriate patients from receiving better care. With a range of new treatments for haemophilia, including gene therapy and other novel therapies such as Epcizumab, Fitusiran and anti-TFPI inhibitors, expected to be licensed over the coming years this will continue to need to be addressed for future commissioning guidance.

Finally, as procurement is led by NHS England, we are concerned that the devolved nations may not be sufficiently involved in decision-making on the availability of treatment. We would welcome clarity on the arrangements that are in place to ensure that the devolved administrations are able to meaningfully contribute to decision-making on the procurement of treatment based on the needs of their populations.

In light of these and other issues, the APPG will be launching an inquiry into the care and support available to haemophilia patients, where we will be exploring how the UK can improve treatment outcomes and respond to the development of new treatments. We of course hope that NHS England and DHSC officials will closely engage with this inquiry and respond to calls for evidence, and would appreciate assurances to this effect. It is also essential that any future tenders for haemophilia treatments support patient access to the best treatments available.

We look forward to your reply.

Yours sincerely,

Diana Johnson MP

Co-Chair of the APPG on Haemophilia
and Contaminated Blood

Sir Peter Bottomley MP

Co-Chair of the APPG on Haemophilia
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Ian Austin MP

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