

# Diana Johnson MP

**Hull North's Voice in Parliament**  
**Labour MP for Hull North**

The Lord O'Shaughnessy  
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Dear

I am writing as the co-chair of the APPG on Haemophilia and Contaminated Blood, to express my concerns about the planned reforms to the English reformed support scheme for those affected by the contaminated blood scandal. Please also consider this as my formal response to the Department of Health's "Consultation on Special Category Mechanism and financial and other support in England."

As you will be aware, the Government set out new details of the support scheme in a Written Ministerial Statement on 6<sup>th</sup> March 2017. I strongly contest many of the points made both in this statement; in the accompanying consultation document and; most especially, in the impact assessment for this proposal – the impact assessment in particular uses some extremely insensitive language, and I will address this later in my letter.

I will set out three concerns about the proposals as they stand.

Firstly and most crucially, I feel that the consultation neglects the fundamental issue, which lies at the heart of all of the concerns raised by APPG members. It is this: whilst the Government has recognised clear needs which need to be met within the affected community, it is not willing to put enough money forward to meet these needs.

Indeed, the Government has followed a curious and flawed process when planning for these new support arrangements. You have announced a review into unmet needs – most particularly for those with Stage 1 Hepatitis C – but you simultaneously set a funding limit before the true extent of these needs had been established. This is no way to address an injustice of this kind, and all of the problems we are now faced with stem from this fundamental failing.

The consequences of this are stark. After consulting with medical experts, the Department of Health has now established, quite rightly, that many of those with "Stage 1" Hepatitis C are in a greater state of need than they realised – I understand from the Impact Assessment that some 50%-70% of the current Stage 1 recipients will

be successful through the Special Category Mechanism. I strongly support this Mechanism, and I feel that the realisation of the extent of unmet need only serves to vindicate the concerns which APPG members have raised over many years about the health needs of people with Stage 1 Hepatitis C. For too long, these concerns fell on deaf ears.

But it is wrong, as the Department of Health does, to then use this fact as an excuse to make cuts to the rest of the support scheme. I therefore do not agree with the proposals to cut the rises in non-discretionary payments in 2018/19 – beneficiaries were promised this support, and this promise needs to be kept. Nor do I agree with the proposals to fund the discretionary budget with whatever is left after these funding commitments have been fulfilled. I would like to reiterate the APPG's view that the Scottish proposals offer a better model for those affected – these come with more appropriate non-discretionary payments and a higher discretionary budget, delivered alongside the same Special Category Mechanism as exists under the English scheme.

It is hard to over-state the degree of concern which these proposals are causing for those affected by the scandal. Until steps are taken to provide additional funding, I regret that there are likely to be divided responses to each of the five questions in the consultation document. Faced with the prospect of severe cuts to their discretionary and non-discretionary funding, people within this diverse community will, understandably, fight to retain what little support they each currently receive. Everyone affected has unmet needs, and each of these unmet needs must be recognised through a single, properly-resourced support scheme. Anything short of this is a gross betrayal of all those who, through no fault of their own, have had their lives impacted by the scandal of NHS-supplied contaminated blood. The consultation questions are understandably being interpreted as an attempt to sew division amongst those affected by the scandal.

Secondly, I must express deep concerns about the uncertainty over the future discretionary budget. The Consultation Document has caused unacceptable uncertainty in the community, by stating that the DH intends to "to keep the scheme within budget in light of the increased annual payment for successful SCM applicants *while preserving the discretionary fund as far as possible.*" The Impact Assessment goes on to use unacceptable terminology when discussing how these and other cuts will be delivered. With respect to the discretionary support, for example, the document states that:

"Reducing or eliminating the overspend will make more money available for expenditure by the NHS on its patients. The social value of these benefits over the whole Spending Review period is estimated as follows."

It goes on to give a "social value" of £73 million to these cuts to the discretionary budget. I have asked two written parliamentary questions about what this will mean in real money, for those affected – one question has given a vague answer, and I am still waiting for a reply to the other. The Department of Health clearly has a figure on what

these cuts will mean, and I would be grateful if you could provide it as a matter of urgency.

The Written Ministerial Statement also announces that the NHS Business Services Authority, rather than a private company, will now manage the discretionary scheme. I still feel that the Government should look at some aspects of the Scottish model for the discretionary scheme. Their discretionary administrator promises to involve users in governance and oversight of the scheme; ensure all existing regular payments under the old schemes are honoured by the new fund; ensure means testing and assessments are "minimised and simplified as much as possible" and put in place an independent appeals mechanism "which involves patient representatives."

Despite asking on several occasions, I am still yet to receive assurance from the Government that no-one will be worse off as a result of the reforms to the English scheme – Ministers have consistently used language which falls short of making anything like a concrete guarantee. Until I receive this guarantee, I will conclude, on the basis of the evidence we have, that many people will face greater hardship as a result of cuts to the discretionary budget – coupled, we now know, with lower-than-promised non-discretionary ongoing payments. Once again, I urge you to provide this guarantee.

I have additionally raised concerns about the interim arrangements in place to fund the existing discretionary charities. Earlier this month, the current Chief Executive of the MacFarlane Trust has written to me to state that they are now due to receive additional funding from the Department of Health until a new scheme administrator is put in place. However, in this same letter, she says she does not yet know whether they will be funded on a pro-rata basis, with sufficient money to maintain support at its current levels. I have asked the Department of Health to clarify in written parliamentary questions but, again, the answers have been vague and non-committal. I write to ask that you clarify this as a matter of utmost urgency.

Finally, I write to reiterate my long-standing concerns about the lack of support for the bereaved. Many of the bereaved understandably feel that with a smaller discretionary fund than promised, they will receive less than they had before. The small £10,000 ongoing payment, which is now being paid out, offers scant reprieve from this, and as stated earlier, many widows have fallen short of the strict eligibility criteria for this. In addition to addressing my concerns outlined above, I would be grateful if you could provide urgent guarantees to widows that they will not be left worse off as a result of these proposals. I have also asked written parliamentary questions about the progress of these £10,000 payments, and I would be grateful if you could answer these as soon as possible.

I can only reiterate my strong feeling that until more funding is announced, I regret that the government's proposals will continue to rightly attract huge concerns and a considerable level of worry amongst a group of people affected through no fault of their own. All of these individuals deserve recognition from the Government that this scandal has had a severe effect on their lives. I remain of the view that all their needs can be met through and a single scheme administrator.

Rather, as stated earlier in the letter, the root issue is more fundamental. It is that the Government, at the same time as recognising there are unmet needs to be fulfilled, is not providing the funding to meet these very needs. This is clearly unacceptable, and I ask that you reflect on the message this sends – not just to those affected by this scandal, but to the victims of future tragedies – about how the British Government addresses injustices.

I urge you now to work openly with the community of people affected by the scandal, and with the APPG, to build a single support scheme which meets the needs of those affected.

As you will be aware, the APPG has arranged to meet with you on Tuesday 18<sup>th</sup> April to discuss these issues. I have been advised by your officials that nobody affected by this scandal can be present in the audience at this meeting. I should stress that two previous Ministers – the Rt Hon Ann Milton MP and the Rt Hon Anna Soubry MP – have previously met with those affected. Indeed, the Rt Hon Ann Milton MP gave assurances that people impacted by the scandal will always be able to meet with her as a Minister. I therefore urge you to reconsider this and reflect on the message this sends, especially at such a crucial stage in the development of the new support scheme.

After you have reflected on this decision, I look forward to hearing from you about the planned meeting.

Yours sincerely,

Diana Johnson  
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cc: Infected Blood Consultation Response, Department of Health, Room 164, Richmond House, 79 Whitehall, London, SW1A 2NS.