

Parliamentary work

APPG and work with MPs

We have been supporting and providing information for many MPs and APPG members to ensure they can fully represent their constituency members and the community as a whole when they have the opportunity to meet with the Minister, officials or the media or ask parliamentary questions, we have also been clarifying points they have raised if we have the information to do so. A total of 4 questions have been asked by MPs with a further 17 waiting to be asked, we hope some will be asked by Lord Hunt in the next few weeks.

An upcoming debate in Parliament

A Back Bench debate has now been approved for Tuesday 12 April at 12.45. If you would like to attend you can ask your MP to reserve you a place, you may need photo ID on the day. Alternatively you can just visit the House of Commons and queue to get in, as long as there is space you should be allowed in. It would be very helpful if you could contact your MP and ask them to attend on your behalf, and ask them to speak. It really helps if you can provide information on how this proposal will impact you (if you know) or any concerns you have, as well as a bit about you. The personal stories are what make these debates so powerful. You can ask your MP to keep you name anonymous if you prefer to do so. In the light of the Scottish announcement it could be key to ask them to highlight the discrepancies between Scotland and the rest of the UK and the discrimination this will create.

Hep C treatment and working with Lord Hunt

Lord Hunt has an interest in Hepatitis C treatment and via our work with the Hepatitis C coalition agreed to meet with us to discuss how he can support our work. We specifically discussed how despite NICE approving many new treatments, a large number of our community are still awaiting treatment and many have been told they are not a priority and may still have a long wait. We also discussed how concerned we are that the DH have set aside money in the proposed consultation to treat our community. This is concerning in many ways, but highlights that the DH have no confidence NHS England will treat people according to the NICE Mandate in a timely way. Lord Hunt is aiming to ask some questions on this issue and ask for a debate in the Lords.

Legality of combining 5 trusts into one

We are aware that members believe the MFT and DH have a legal contract with beneficiaries that may impact the government ability to cease payment or close the Trust. We are seeking clarification on this point, via a Freedom of Information request.

Meeting with the Department of Health

Diana Johnson MP was contacted by officials at the Department of Health and offered a meeting for the secretariat of the APPG with DH officials who are working on the consultation proposal. There was very short notice, but Liz Carroll was invited to join a member of Diana's team at the meeting.

Overview of issues covered

The meeting was just an hour and was to discuss the proposal and consultation process. We were able to highlight that this proposal will leave many (particularly MFT registrants) in a significantly worse financial situation that would be devastating to their lives and leave others with a great deal of uncertainty (mainly Skipton and Caxton registrants). We were able to highlight a small number of

particular situations such as widows and partners, children, and those with HIV who receive significant but regular discretionary payments.

Stage 1 assessments

We also discussed the huge concern over the assessments for stage 1, including that they could be carried out by someone who has no understanding of the impact of multiple conditions (Hep C, haemophilia, vCJD etc.) and how multiple diagnosis can amplify the effect of a condition. We pointed out that the need for reassessment causes financial uncertainty and stability, and suggests people may receive less money if they have treatment and respond well.

Official's response

The officials did not respond on any particular points, except to say there is a defined budget for the next 5 years and as they wish to include people with stage 1 so they have the opportunity for ongoing payment if this has impacted their health, it may well mean some people receive less money, but they want to hear from those affected how they feel about this in their consultation responses.

Widows concerns

We also asked them to clarify some specific points on the proposals impact and inclusion of widows and partners as there are many different categories and the document does not make it clear who is or is not included. We highlighted that some widows and partners have never received any payments for their partner' such as widows and partners of people who died from Hep C or infected partners who's partner had died, and these have not been addressed in the proposal. We are awaiting the DH response as they were not able to answer this during the meeting.

Process of the consultation and uncertainty on how to respond

Other areas highlighted were that The Society and many MPs have received calls from people who do not understand the consultation questions, or the impact it will have for them personally and so feel unable to give an informed response, as well as from people completed the response early, but now have realised there are important things they have missed. The DH officials said people could submit a second response with additional information. They confirmed every response so far seems to be from someone who has a good understanding of the situation, and has ticked a box to say they are affected in one way or another. They said many people are completing the document using the free text boxes to say things that don't quite fit that particular area of focus, but these responses and comments will all be included.

Timing of the final decision

A further key point was that we asked when the government response may be published. Due to local elections and the referendum, they were unable to give us a date, but the implication was it could be summer or even later.

Wales and Northern Ireland

We asked the DH officials to clarify how their proposal will impact Wales and Northern Ireland. They confirmed that this is a proposal for England only, but also informed us that the Welsh and Northern

Irish Government have asked to see the results of this consultation to help inform their own decisions. In light of this we believe it is important that the affected community from across the UK take this opportunity to make their thoughts heard via this consultation as it may influence the outcome in other parts of the UK.

Legal advice

We recently met with Leigh Day solicitors to discuss what legal options we may have as a charity to stop the current consultation or make representation to have the most impact. This was on the recommendation of the law firm who represented the community in Ireland. Their area of law focusses on Public Law, so they specifically looked at whether the consultation process is legal. There may be some areas of uncertainty here, so we have asked them to investigate this further. We will then need to consider how The Society responds as any legal action would have a significant impact on our financial situation and could impact future sustainability as a charity. The Board of Trustees will consider this further when we have more information about whether there is a case to be made.

Seeking treatment options for people with Hepatitis C who have not yet received treatment.

We are aware many of our members have now received Hepatitis C treatment with the new generation of drugs, but many are also still waiting and have been informed they may have a long wait due to NHS England Prioritisation criteria. We do not believe this is acceptable so have been investigating whether using the European Health Directive may enable people to access treatment elsewhere in Europe with the NHS providing payment. More work is required to fully understand if this is possible and the implications for individuals.

Scotland announcement

Following the announcement in Scotland on Friday, we have been reviewing the impact for those affected in the rest of the UK.

We believe the Scottish settlement is a very positive step forward and will have a significantly positive impact for many of the community there. However we recognise that for those with stage 1 Hep C there is still some way to go before the full impact of this tragedy has been recognised. We congratulate Haemophilia Scotland and the many campaigners there in securing a much improved settlement for those infected in Scotland. We will continue to call for the current England proposal to be revised and will use the Scottish situation to highlight the discrimination now evident for people living outside of Scotland.

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