

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN0381001

Exhibits: WITN0381002-9

Dated: August 2019

**INFECTED BLOOD INQUIRY**

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**EXHIBIT WITN0381006**

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DoH PROPOSALS TO REFORM THE INFECTED BLOOD PAYMENT SCHEME – January 2016  
SUMMARY SCHEDULE OF COMMENTS IN RESPONSE TO CONSULTATION - SHEET 1 of 15

Ref:- 11.02.20.1.1  
13.04.16

## 1.0 INTRODUCTION

1.1 I declare that I **GRO-B** has a personal interest in this matter as being one of the English registered haemophiliac/bleeding disorder victims and survivors infected with HCV by treatment with contaminated blood/blood products whose lives have been significantly and adversely affected by this tragedy.

1.2 Despite the reluctance, extreme anguish, difficulty and agony of doing so and whilst, as referred to in emails messages previously, Item 2.0 refers, I still prefer to be otherwise and there be no such need at all I am nevertheless and do once again feel provoked and compelled to respond further and in summary terms as it is clear that based upon these reforms there is no dignified or just closure for the victims and survivors of this tragedy in sight as there should be.

1.3 Despite the utmost excruciating challenge and anguish of doing so this response is made as a matter of principle and with a sense of moral obligation especially mindful of other victims and survivors who have fading or no longer have the will, strength or a voice at all, in order to at least register the utter despair, discontent, dismay, dissatisfaction and disappointment with this current and most shameful situation.

1.4 Neither must it be forgotten that this tragedy, which is well recognised as being the worst treatment disaster in the history of the NHS, is one which was avoidable but did instead infect and has already cost the lives of approx. 2400 and destroyed the lives of other victims and survivors suffering with haemophilia and other bleeding disorders treated with contaminated blood/blood products for whom there has been no just closure.

Such unresolved circumstances do therefore unjustly prolong the victims and survivor's agony as they do and these reforms and consultation provide an indication that this government is continuing with either ignoring or and despite what it claims has no real idea about or understanding of the circumstances and the devastating impact upon the victims and survivors of this tragedy as it should.

1.5 There are of course other individual victims, survivors, bereaved, dependants, carers etc and various interest and support groups involved with this situation for example The Haemophilia Society, The Hepc Trust, Tainted Blood, 38degrees and The Contaminated Blood Campaign who has stated aims and has apparently instigated proceedings in connection with this tragedy and perhaps others who may or have in their own way also expressed comments, concerns and opinions with regard to their dissatisfaction with these reforms and consultation.

1.6 Unlike government victims and survivors are in the main and like me individual lay citizens who are isolated from and without the equivalent benefit of intense professional guidance, advice and experience on their side which is by comparison an obviously serious disadvantage to them when responding to these reforms and consultation and the implications of doing so.

It is therefore of some concern to have noted from the minutes of the APPG 09.02.16 meeting reference to Liz Carroll being called upon to provide a summary of the consultation and The Haemophilia Society's findings to date to the APPG as it appears to be a task for the APPG as a whole measured against its expectations.

In this and with all due respect to Liz Carroll and the Haemophilia Society whilst obviously involved with the haemophilia and bleeding disorder community this is, given the unresolved nature of the current situation, a most challenging onerous of tasks and responsibility especially due to the potentially serious implications of providing such a response to the APPG that could in turn influence the outcome and affect it would have upon the victims and survivors of this tragedy.

This is especially the case when bearing in mind the apparent complexity of this situation, the shortcomings, discontent, lack of clarity and limited information upon which these reforms and consultation have been based for which formal suitably qualified professional, probably legal, involvement, advice and responsibility is required and would be appropriate but potentially compromised without the benefit of any such recourse being to hand or readily available.

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1.7 This Summary Schedule of Comments has been prepared having been prompted and provoked by the Department of Health's letter dated 21.01.16 to victims regarding the statement in the House of Commons by the Health Minister, Jane Ellison MP, on 21 January 2016 and DoH document in connection with and the proposals to reform and consultation upon the system of support for victims and survivors of this tragedy.

## 2.0 INITIAL/INTERIM RESPONSES

2.1 Following receipt of the DoH's letter and a cursory appraisal of it initial responses to this consultation were sent by email messages to the APPG and copied to The Haemophilia Society dated 02.02.16, 10.02.16, 18.02.16, 05.03.16, 07.03.16, 2 dated 15.03.16 which are relevant to this consultation.

2.2 A subsequent series of initial/interim response email messages have also been sent to the Infected Blood Reform Team which were also copied to members of the APPG and The Haemophilia Society and have been incorporated into this document as follows:-

1 GRO-B IBRT email dated 15.03.16

*'The Infected Blood Reform Team*

*Whilst I prefer it to be otherwise and there be no such need I nevertheless feel compelled to write as an initial/interim response to the IBRT with regard to the proposed Reforms and Consultation upon this tragedy as and for one reason or another I may or may not be able or in a position to provide more.*

*In this respect and summary terms please note that following receipt of the DoH letter dated 21.01.16 and being provoked by it some email messages have been sent previously to members of the APPG and The Haemophilia Society upon which this email message to the IBRT has been based.*

*In this respect and no doubt like other victims and survivors the opportunity is taken to note that I for one have been unable to avoid thinking about all of this and the myriad of dark thoughts and emotions that have recurred and have frequently arisen on a constant daily basis which I have been unable to prevent all of which, and as it has before, is proving to be very painful and has/is making me feel very unwell indeed.*

*However I, other victims, their families and others affected by and/or involved who are on the victims and survivors side of the fence of this tragedy have, during the course of an extremely prolonged and exhausting period of time, already contributed a great deal more than is enough and adequate towards the understanding and just resolution of this tragedy.*

*Having done so it has to date proven to have been a virtually futile endeavour, however it is no longer necessary and there is no such need for any more reiteration, additions, further representations, meetings, protests, consultations etc from the victims of this tragedy nor any others as is now proposed and required by this government.*

*Enough is enough, all that needs to be known is known, all that needs to be said has been said, all that needs to be done has been done and I for one am exhausted by it, however what government needs to do in order to bring this tragedy to a prompt meaningful comprehensive closure without further ado has not and shamefully remains outstanding.*

*This government has now demonstrated that it is following in the shameful footsteps of all of those before it by knowingly and deliberately continuing with a destructive strategy to wage what amounts to a psychological war of attrition against the victims of this tragedy.*

*This strategy has obviously been successfully deployed by governments in the past and by means of such procrastination and continual recycling it continues to deny, obfuscate and complicate that moves development backwards towards the beginning to start the process over again rather than forwards towards closure which is once again as distant as it has ever been.*



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*Furthermore additional provocation was caused by hearing that the APPG's request to meet with the Minister Jane Ellison MP in order to discuss these proposed reforms, consultation and initial responses to them was apparently refused 'whilst the consultation is in progress'.*

*This is a further and shameful response by this government which indicates that it is unlikely that anything different and/or meaningful will be forthcoming from this government as it should and would in turn result in the prompt full fair and just closure of this tragedy as is long overdue and required.*

*Accordingly the victims of this tragedy have already endured and suffered more than enough and who's health and wellbeing is now being further adversely affected by this current appalling and most devastating situation the serious shortcomings of which amounts to a disgraceful farcical sham that should be condemned, withdrawn and not responded to by the victims and survivors of this tragedy and all others on the same side of the fence.*

*This is a somewhat desperate measure despite which and mindful of such circumstances I also urge and request IBRT to it pursue please especially as there seems to be no point and there is little if any strength or capacity left for the dead and exhausted victims and survivors of this tragedy to accommodate, cope with and respond to this consultation as things stand and who's voices have not really been heard before and it appears that despite whatever we do or say now they will not be really be heard in the future, if at all.*

2 **GRO-B** IBRT email dated 21.03.16

*'Infected Blood Reform Team*

*Whilst I continue to prefer it to be otherwise and there be no such need I nevertheless and yet again feel compelled to write further to my previous message and as a further part of an initial/interim response to the IBRT with regard to the proposed Reforms and Consultation upon this tragedy as and for one reason or another I may or may not be able or in a position to provide more.*

*In this respect and summary terms further provocation has arisen in particular caused by news of Iain Duncan Smith's resignation due to proposed PIP cuts and the subsequent announcement that this proposal is now apparently to be shelved and 'not go ahead in their current form' which and whilst such matters are separate from and are in many ways different from those of this tragedy there are in principle similarities and comparisons to be drawn from such an action.*

*Accordingly and as there has been no response to the previous message and request to do so I take this opportunity to reiterate the request that government also withdraws these reforms and consultation upon them without further ado.*

*In the meantime and since my previous message I recall and it has once again occurred to me that and for example:-*

1 *It is the first duty of State is to protect its people, however this was clearly not the case as far as this tragedy is concerned.*

*It has been and still is a disgrace that successive governments have failed but not acknowledged or accepted any responsibility whatsoever and as they should and must do.*

2 *Successive governments in England have continually denied victims and survivors a meaningful Public Inquiry into the contaminated blood/blood products tragedy as is still required as has, for example, been the case in other tragedies:-*

*Hillsborough, Bloody Sunday, Staffordshire Hospitals and Saville four amongst others long denied but eventually afforded the Inquiries they deserved and from which some ugly facts and truths eventually emerged that had previously been shamefully covered up and concealed from public view.*

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3 *Successive governments in England have not cooperated to the full extent necessary in and to the process of investigation and have not been formally called upon to give evidence under oath and held fully to account all of which remains outstanding as is still required.*

4 *There have been no criminal investigations in England into the contaminated blood/blood products tragedy especially whether or not there has been any criminal action, crucial information and/or evidence having been withheld, 'shredded', interfered and/or in any other way improperly tampered with and by so doing perverting the course of justice as is still required.*

5 *There has been no legal or other action by successive governments against the manufacturers and suppliers of the contaminated blood/blood products which caused this tragedy as there should the proceeds of which could help with and contribute towards the victims and survivors of it.*

6 *It has for a considerable period of time been apparent that and in the absence of any such meaningful Formal Public Inquiry, criminal investigation, lack of government's cooperation and their denial in England the just and fair closure of this issue appears to be increasingly dependent upon alternative proceedings to achieve any such final closure as is required.*

*As closure of this tragedy has been moved further away these are I believe some reasonable, good and typical examples of the so called 'System' of this Nation being seriously out of balance and heavily biased towards the establishment and against the 'public' and the 'public interest' and in this particular instance the victims and survivors etc of this tragedy which I consider to be unreasonable, significant and somewhat unjust 'David and Goliath' type factors to be taken into consideration and account now about which I urge and request the IBRT and this government to pursue.'*

The items referred to in this particular message have also been expanded upon and incorporated into this document under 3.0 GENERAL Items 3.1 – 3.7

3 **GRO-B** – IBRT email dated 23.03.16

*'Infected Blood Reform Team*

*Whilst I continue to prefer it to be otherwise and there be no such need I nevertheless and yet again feel compelled to write further to my previous messages and as a further part of an initial/interim response to the IBRT with regard to the proposed Reforms and Consultation upon this tragedy as and for one reason or another I may or may not be able or in a position to provide more.*

*In this respect and summary terms I have been prompted in this particular instance by news of the proposal, in Scotland, for a Memorial to the victims of this tragedy with which I agree in principle, however I am somewhat disappointed and saddened by it not representing the UK as a whole and that England has no proposal for a Memorial at all and as it should.*

*A Memorial is something of significant importance to this tragedy to which I have coincidentally referred previously as and for example by email message to members of the APPG dated 16.12.16 and The Haemophilia Society dated 15.12.16 which is summarised as follows:-*

From: **GRO-B**  
Date: 15/12/2015 - 13:04 (GMTST)  
To: lizcarroll@ **GRO-C**  
Subject: CHRISTMAS HQ

*Hi Liz, Thank you for your Christmas message:-*



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Dear Member, Welcome to the Christmas edition of HQ, etc  
Liz Carroll Chief Executive  
The Haemophilia Society UK<sup>1</sup>

To which I feel compelled to respond.

The Society's 65th year is an amazing achievement but sadly another that has passed and not witnessed as it should final closure of the contaminated blood products issue and the devastating impact it has had especially upon the haemophilia/bleeding diseases community to which the most sad HQ Winter 2015 article '25 years of remembrance' and attached illustration refer.

After so much time and suffering the opportunity that the forthcoming New Year now offers for final closure to be achieved most promptly and without further ado has surely arrived and must not be pushed back and missed again.

There is also a need for these tragic events to be formally and properly recognised by means of a permanent memorial which I have raised previously with the Society to which and for example my message dated 03.03.13 refers and is as follows:-

'From: [redacted] GRO-B  
To: Chris James - HSoc <chris@[redacted] GRO-C>; Dan Farthing <dan@[redacted] GRO-C>  
Sent: Sunday, 3 March 2013, 14:37  
Subject: Re: Fwd: Contaminated Blood Consultation

Hi Chris and Dan

I feel compelled to write having been prompted on this occasion by hearing news of the 70th anniversary Service and the albeit belated unveiling today of a permanent Memorial sculpture to the victims of the 'worst civilian disaster of WW2' in which 173 people of which 62 were children died at Bethnal Green Tube Station.

As I understand it reporting of this tragedy was apparently censored at the time and there were also accusations of a deliberate government cover up a matter not unfamiliar to the contaminated blood/blood products issue.

However and once again whilst not the same this is another example whereby comparisons can be readily made to the Contaminated Blood/blood products issue in which case it now occurs to me that the campaign objectives should also include and call for a significant permanent Memorial to be erected in a very visible public place in London near to the seat of government (Parliament Square perhaps?) to mark the 'worst tragedy in the history of the NHS' that would be an appropriate gesture to all its victims and suffering caused by it.

It would of course be better still if such a memorial were also to include formal recognition of just resolution and closure which do of course remain shamefully outstanding at this point in time.

Regards

[redacted] GRO-B

Accordingly I request and urge you and the Society to pursue such necessary courses of action with the APPG and any other appropriate authorities please.

Regards

[redacted] GRO-B

I note with some interest that one of the recipients of the message dated 13.03.13 was Dan Farthing who and following his time with The Haemophilia Society in England took up a similar position in Scotland where he appears to have had some influence and success with this particular proposal which I urge and request the IBRT, APPG, The Haemophilia Society and this government to also pursue as noted please.

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The matter of a Memorial as referred to in this particular message has also been incorporated into this document under following item 8.0 MEMORIAL.

## 4 **GRO-B** – IBRT email dated 27.03.16

*'Infected Blood Reform Team*

*Whilst I continue to prefer it to be otherwise and there be no such need I nevertheless and yet again feel compelled to write further to my previous messages and as a further part of an initial/interim response to the IBRT with regard to the proposed reforms and consultation upon this tragedy as and for one reason or another I may or may not be able or in a position to provide more.*

*In this respect I have in this instance been unable to avoid and have been prompted by painful recurring thoughts of the lost opportunities and shameful failure of successive governments to bring due just closure for the victims and survivors of this tragedy a situation which continues to prevail and the more such thoughts arise the less belief, faith, and trust there is in this reform and consultation process to do so for example:-*

*It is generally understood that the design and content of consultation/survey type questionnaires is something that is very carefully considered and fabricated by professional experts and those behind it that is intended and can then often demonstrate an outcome which has been manipulated, biased towards and to their advantage.*

*This awareness can in turn and does cause those who have been specifically invited to participate in the process, eg the victims and survivors of this tragedy, to be suspicious and have insufficient or no trust at all in a process upon which they cannot rely or depend to bring about due just closure as is the case with these reforms and consultation process.*

*Despite what it purports to be this has signs and indications of government having already made up its mind and reached a decision whilst reluctant and/or lacking courage to honestly admit to or openly share it.*

*This is making a presentation of rather than offering a consultation upon these reforms an inappropriate process that will no doubt and if it continues result in further confrontation, disagreement, complication, obfuscation and prolongation rather than due just closure for the victims and survivors of this tragedy as could, should and needs to be the case.*

*As far as this consultation process is concerned government has not made as clear as it should and now needs to clarify by whom and what means the responses to this consultation process are to be collated, analysed, verified, reported upon and made public in order that they can then be reviewed, conclusions reached, agreed upon and implemented as the final act of closure for the victims and survivors of this tragedy.*

*In the meantime it does appear that and on the somewhat bare face of it to be a reasonable and sensible proposition to replace the five current payment schemes with one, however without full explanation, details and clarity of such a change it is not possible to reach a properly informed decision about it especially as it may in some undisclosed way vitiate, diminish or perhaps avoid payments being made altogether and come in at an unacceptable 'cost' to the victims and survivors of this tragedy.*

*In this respect it is apparent that there is no reference in these reforms to the fundamentally important matter and provision of automatic increases to scheme payments as there needs to be.*

*It is not a matter of being ungrateful for the HCV related payments received, however they are relatively and comparatively meagre and should therefore be automatically increased and means of backdated type payments made for having been delayed and avoided for so long.*



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*Payments to victims and survivors should not be subject to or dependent upon means testing, medical assessment, begging or taxation.*

*Those already and the newly bereaved should receive payments as a form of 'inheritance' and be sufficient and adequate to support widows, partners, dependants etc.*

*All bleeding disorder victim infected by treatment with contaminated blood/blood products but not yet registered with an existing scheme should automatically 'qualify' for, join the scheme and receive due and just payments.*

*Furthermore and whilst writing I take the opportunity to also mention that and with the obvious exception of treatment with contaminated blood/blood products I am not ungrateful for the treatment and care that I have and do receive and that the best of HCV, HIV (and any other) treatment should be readily available to all bleeding disorder victims and survivors of this tragedy who were treated with and infected by contaminated blood/ blood products.'*

The matter of Payments as referred to in this particular message has also been expanded upon and incorporated into this document under following item 4.0 FINANCIAL SUPPORT.

5 **GRO-B** – IBRT email dated 02.04.16

*'Infected Blood Reform Team*

*Whilst I continue to prefer it to be otherwise and there be no such need I nevertheless and yet again feel compelled to write further to my previous messages and as a further part of an initial/interim response to the IBRT with regard to the proposed reforms and consultation upon this tragedy as and for one reason or another I may or may not be able or in a position to provide more.*

*In this respect and since the last message in this trail dated 27.03.16 some further thoughts have arisen with particular regard to the 'payments' aspect of this tragedy which are summarised as follows:-*

1 *The Minister has made the point and said that whilst monies have been identified it is not, apparently, appropriate to talk about 'compensation' payments in connection with this tragedy, for 'legal' reasons which and as they are not need to be clarified by government especially as the term 'compensation' appears to be an appropriate form of terminology as far as closure for victims and survivors of this tragedy is concerned.*

*Whilst there may be a more politically acceptable alternative word or form of terminology whatever it may be these reforms are not but must be fair, just, meaningful, comprehensive and not discriminate between differing affected groups in order to promptly bring about the long overdue closure for the victims and survivors of this tragedy for once and for all and without further ado.*

2 *The Minister has also made the point and has said that as far as regular financial support is concerned 'no amount of money could ever make up for the impact this tragedy has had on people's lives' and however true that is it is not an excuse or reason for the amount not being fair, just, meaningful, comprehensive and not discriminate between differing affected groups in order to promptly bring about the long overdue closure for the victims and survivors of this tragedy for once and for all and without further ado.*

3 *Apparently financial support for the victims and survivors of this tragedy is intended to be funded from the NHS budget that would be inappropriate and to which I object, especially as it appears that this is a deliberate government ploy to minimise and/or avoid any such payments due in part to the detrimental affect it would obviously have upon the NHS and consequential potential for negative public opinion and affect arising from it that could be deflected towards and against the victims and survivors of this tragedy.*



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*Instead financial support for victims and survivors of this tragedy could, should and needs to be from an alternative National/Treasury type resource as is for example often the case in other National/International disaster/tragedy situations that arise, require and result in a specific government response to and funding as would be appropriate in this instance.*

*Furthermore the establishment and management of any payment scheme should not be 'subcontracted' out by government to a private independent non-governmental organisation but form instead a specific part of an established government department, perhaps DW&P?, so as to be fully responsible and accountable for the scheme by persons qualified, responsible and publically accountable for doing so.*

*News of vast sums of public money being allocated for various other reasons frequently arises on a regular basis so much so it has become an almost daily 'norm' each one of which passes from public gaze and news in an instant to make way for the next and are too numerous to recall but one referred to previously is for example summarised as follows:-*

*As well as the significant nationally funded original cost and long term sustainable legacy aspirations that drove it the subsequent additional sum of £750/800m all apparently 'given' to West Ham football club as part of the 'deal' for the conversion of and to assist them towards their occupation of the Olympic Stadium which does, to all intents and purposes, appear to have been given away without much in the way of hindrance or fuss in a similar way to that of the Millennium Dome at a cost to the Nation of £800m and sold on to an overseas organisation shortly afterwards for £1 and who are apparently profiting from it without the hindrance of any 'pay back' deal to balance the National books.*

4 *Whilst it is not clear why or how these reforms would apparently and in one way or another cause some victims of this tragedy to be worse off than they are at present the actual reasons for which and details of are not and need to be made clear but would almost certainly not be a right, proper or an acceptable 'reform'.*

*It appears that these reforms do not include, as they should, new and/or increased payments being backdated in order to account for the prolonged period of time now elapsed during which victims and survivors were infected and affected by the devastating impact that this tragedy has had upon their lives.*

*It is acknowledged that these reforms do refer to the provision of miscellaneous payments being made, as they should, to victims and survivors for reasonable unavoidable expenses incurred for travel and accommodation etc necessary and related to receiving treatment in order that they are not financially disadvantaged by doing so.*

*This is especially the case with regard to the care of haemophiliac and other bleeding disorder patients is concerned as the number of treatment centres has been significantly depleted from what it once was to what it now is that presumably requires less funding but does of course make it more difficult for patients to travel to and access treatment and follow up purposes especially if in some way or another incapacitated and/or suffering with mobility difficulties.*

*The concept and establishment of Centres of Excellence is understood however whilst they have a place being fewer, thinly spread and further apart as treatment centres now are they are not as readily accessible to patients who are not living nearby that is as such not sufficiently compatible with the nature and type of treatment needs, care, follow ups etc of haemophiliacs and other bleeding disorder patients need.*

*Therefore this situation does little to improve and provide such treatment needs for haemophiliac and other bleeding disorder patients affected by such closures and is far from and not the more Comprehensive Care patients once had, were promised and depended upon but these closures have no doubt significantly reduced the cost of providing what now exists of a service to those patients left and/or in need of and who are otherwise not ungrateful and thankful for it.*

*I have written on several occasions in the past to UKHCDO with regard to such closures and associated concerns that have been shared with others directly involved to which and despite the gravity of the situation there has sadly been no response to suggest that any change will be forthcoming as it should.*

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6 **GRO-B** - IBRT email dated 09.04.16

*Infected Blood Reform Team*

*Whilst I continue to prefer it to be otherwise and there be no such need I nevertheless and yet again feel compelled to write further to my previous messages and as a further part of an Initial/interim response to the IBRT with regard to the proposed reforms and consultation upon this tragedy as and for one reason or another I may or may not be able or in a position to provide more.*

*In this respect and since the last message in this trail dated 02.04.16 some further thoughts have arisen with particular regard to the proposed 'Health Assessment' aspect of this tragedy which are summarised as follows:-*

## 1.0 PROPOSED HEALTH ASSESSMENT

1 *With the obvious exception of treatment with contaminated blood/blood products I and no doubt other haemophiliacs and bleeding disease patients are not ungrateful for treatment and care that they receive.*

*In this respect and the depletion of centres aside it is acknowledged that there have over the years been significant improvements with treatment in particular and for example and prompted by this tragedy the availability of recombinant products which are by comparison with all that preceded it efficacious, convenient and most importantly safe at least as far as we are currently aware.*

*However perhaps like me others may have almost certainly 'had enough' of the treatment and care interventions upon which they depend and are necessary and do all that they can to take care to and avoid them.*

*That being the case for the onus to be placed and fall upon victims of this tragedy to somehow demonstrate to new and unfamiliar persons involved with any such health assessment but without previous understanding or any awareness of the individual victims, their case history or how the impact of their infection has/is affecting their health during its perhaps complex long term course is unreasonable and unacceptable.*

*Any such health assessment proposal represents as it does a form of unnecessary obscene degrading humiliation for victims and survivors who would be required by it to go cap in hand begging for such discretionary or charitable payments as would if implemented be the case with this shameful proposal.*

*Instead of being subjected to such health assessments it should be and is sufficient to know, as it is, that registered haemophilia and bleeding disorder victims have been infected by treatment with contaminated blood/blood products in which case there is no need for the imposition of any additional individual health assessment and subsequent reassessment as they have no place or appeal whatsoever and should therefore be abandoned.*

2 *If implemented these reforms propose to dismiss and exclude haemophilia and other bleeding disorders from being taken into any account and consideration when determining any such annual payments attributable to having been infected by treatment with contaminated blood/products would be incorrect, unreasonable and unacceptable.*

*Instead the devastating impact that this tragedy has had upon victims and survivors needs and must be seen through the specific lens of also having and the burden, blight and hindrance of having haemophilia or other bleeding disease.*

*These factors need to be taken fully into account and consideration together with the consequential detrimental circumstances arising from the combined individually unique range of complex, physical and psychological affects which are unavoidably magnified by such a lens and circumstances.*



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3 *These reforms do not make clear what criteria is to be applied for carrying out and evaluating the individual health assessments nor by whom or how any such judgement will be made.*

*Such a process would obviously require considerable expertise and intimate knowledge of the highly complex considerations involved despite which it appears and would almost certainly prove and be practically impossible to fully and adequately quantify, evaluate and accurately assess each individual victims case, its intimate history, circumstances and the wider devastating detrimental impact has had upon the lives of victims and survivors of this tragedy.*

*If implemented what such a process cannot be is some form of bargain basement 'tick box' type assessment carried out on a lowest bid cut price sub contract commercial basis by inappropriately qualified people and/or organisations who may and probably would be incentivised to reject any such application and payment as was for example the case with the highly controversial Atos and other such organisations who have been involved with other similar disgraceful employment, welfare/support type assessments in the past.*

## 2.0 IMPACT STATEMENT

1 *The 'Impact Statement' of each of the individual haemophiliac and other bleeding disorder victims and survivors of this tragedy will differ considerably due to the wide ranging and highly complex nature of their experiences, circumstances and the devastating detrimental impact that the stigma of and this tragedy has had upon their lives.*

*However what the victims and survivors of this tragedy are most likely to have in common are the numerous, significant, physical, psychological, mental health, traumatic and various other ways that they have personally, suffered from and been adversely affected by this tragedy.*

2 *I confess that I have not been at all sure about or comfortable with sharing in this way what is for me highly sensitive personal information for the purposes of this consultation especially as I prefer it not to be in the public domain, however on balance I feel, believe and have concluded that it does, given such circumstances and in summary terms, have some relevance to this process.*

*In this respect there is no doubt whatsoever that having haemophilia, or any other bleeding disease, is a burden which has alone blighted and hindered my own, and probably the lives of others in similar circumstances, during the course of which and having also been infected with HCV by treatment with contaminated blood/blood products it too has had an enormous additional adverse detrimental impact upon it.*

*The combined effect of such a situation has, for me at least, been a truly life changing experience which has devastated it from a general wellbeing, physical and psychological/mental health point of view etc with which I have and continue to struggle and have been unable to adequately cope and function on a normal daily basis.*

*However whilst life has altered it 'goes on' albeit in a less than 'normal' way based upon a far more isolated withdrawn one step at a time 'day to day' type approach not daring to venture, look or plan ahead as would otherwise and normally be the case but has instead been replaced by a general paralysing sense of insecurity, misery, dread, fear of deterioration and prospect of death.*

3 *The routine and prospect of normal life, enjoyment of and what goes with it have been severely diminished, personal relationships over tested, career and employment disrupted together with its financial insecurity, insurances complicated, problems with travelling etc which have instead been forever altered by such circumstances.*

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*There is no doubt that 'damage has been done' and during the course of an unrelenting dark period of time it has not been possible to avoid the anguish, anxiety, stress, depression, fear, traumatic effects, prospects and the daunting overwhelming mind clogging thoughts, procrastination and sleep deprived nights that goes with it from which there has been no respite but instead realisation it has not been and will not be possible to ever be able or come fully to terms with, overcome and recover from such experiences which are in one way or another present on a constant daily basis.*

*This extent of the grief and impact of this burden has been and is immense, beyond adequate description and not a day goes by without also giving thought to wondering about how, thus far, and in some truly astonishing way, I am surviving despite having been injured by but having 'dodged the bullets' that have so tragically killed other trusting people who have also been unwitting innocent victims of this tragedy and may as such have also been unwitting innocent guinea pigs of it too.*

4 *Haemophilia and bleeding disease sufferers are of course also mindful of the existence and exposure other such infections due to treatment with contaminated blood/blood products such as for example is the case with vCjd and the chilling formal public health warning registration letter we have received about it and who knows what, when and how many other such infections there are to challenge us all further still and as they reveal themselves in a similar way to HCV and HIV.*

5 *There is of course a great deal more to HCV than liver disease alone especially the impact that such complex things and their side effects have had on normal life which and whether they be known about or not cannot and must not be disregarded in bringing due just closure to the victims and survivors of this tragedy without further ado, as a matter of urgency and before we do all die.*

2.3 The APPG and IBRT have previously been requested and urged to take the necessary formal action on behalf of the victims, survivors and others involved to cancelled and withdraw these reforms and consultation as a matter of some urgency and in order to avoid any form of default that may in some way or another give it undue advantage, credit or influence.

However no such response has been received to this and as it still is evident that there are serious fundamental shortcomings with these proposed reforms and consultation it has no reputable place, is not necessary and should, as previously requested, be formally recognised as being invalid and withdrawn.

## 3.0 GENERALLY

3.1 Most recently The Penrose Inquiry and report in Scotland apparently amounted to a cowardly whitewash and offered nothing upon which closure could be based.

Prior to Penrose Lord Archer's Inquiry and report upon it included amongst other things recommendations for what appeared to be a reasonably acceptable basis, compatible with arrangements elsewhere, upon which closure to this tragedy could be based as has for example been the case elsewhere.

However Archer has instead been substantially ignored, overlooked and regulated by successive governments into virtual obscurity rather than taken into consideration and used as a steer towards due and just closure as it should and before those of us who survive get much older and/or also die.

3.2 Along the way there have been occasions and indications that the need for due, dignified and just closure had been acknowledged, was well enough understood and within close and readily available reach circumstances which in turn renewed the trust of victims and survivors that and at long last meaningful closure be forthcoming.

Instead successive governments have during the course of a monumentally prolonged period of time betrayed any such trust by continually resisting, frustrating and treating victims with contemptuous disrespect and contriving to ignore, delay, disregard, complicate, erode, diminish and move any such closure ever further away or perhaps and as repulsive as it is to deny and avoid it altogether.



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This appears to have been by means of adopting a despicable underhand policy designed and deliberately intended to deter and grind us down, reduce our time left or wait for us to die mindful that there are many whose time has already passed or is now short as indeed has proven to be and is the case.

3.3 Victims and survivors of this tragedy have already suffered and endured enough by which I for one am exhausted and to be 'invited' by government to apply themselves yet again and in any such excruciating manner to this issue, closure and all that goes with it in the way of memories, depression, stress, anxiety and anguish is a shameful disgrace.

This is especially the case when bearing in mind the painful history of, considerable passing of time, the many victims and the serious shortcomings, failures and appalling comparatively dismissive attitude of successive governments towards this tragedy, its victims and their suffering all of which is shameful and unjust.

3.4 Despite what has been taken into account, provided for to date and the PM's perhaps somewhat insincere apology in the House last year (perhaps having an awareness of what was already in hand and to later transpire as it has?) and all that has preceded it these are obviously not the fully comprehensive reforms necessary and required to bring about full and meaningful closure for the victims and survivors of tragedy that it attempts, purports but fails to be that will not as such bring about closure to the extent necessary to do so.

3.5 It verges on the obscene to again and now 'invite' and thereby oblige victims and survivors of this tragedy to scrutinise these latest and somewhat complex reforms to the full extent necessary to respond in a fully informed and comprehensive manner, whereas the reasons have already been made and are clear enough to fully justify and carry this tragedy to a point of long overdue closure it deserves.

Despite this it is clear that these reforms represent yet another dubious example of a governments 'smoke and mirrors' approach and contrivance masquerading under the definition of 'Reform the Infected Blood Payment Schemes and 'system of support' that attempts to avoid and conjure an illusion of being a genuine attempt to produce the comprehensive reforms required but do not.

Instead successive governments have continually contrived devious ways and means to substantially ignore and dismiss them and fabricate pathetic ongoing reasons and excuses so as to avoid and/or delay the positive action which remains necessary and urgently required to be taken by government in order to bring about such meaningful comprehensive closure.

3.6 The current situation is yet another shameful example of government's deplorable confrontational attitude, denial and lost opportunity for it to gain respect by and at long last do the right, proper, moral and honourable thing by bringing about dignified due just closure for the victims and survivors of this tragedy as should, could and needs to be the case.

3.7 The email message to IBRT dated 21.03.16 referred to above under item 2.2.2 includes a reference to the recent resignation of Iain Duncan Smith apparently on the grounds of undue pressure upon him to agree to and accept against his better judgement cuts in welfare support is a further indication of such things having gone way to far towards balancing the books a situation since acknowledged by the Prime Minister and in Parliament by the Chancellor as being subject to reconsideration as should now be the case with these reforms and consultation.

## 4.0 RE - 'TURNING TO THE INFECTED' - FINANCIAL SUPPORT

4.1 Whilst Initial/Interim comments have been made previously with regard to financial support and payments are referred to in the email message included under item 2.8.4 & 5 above the opportunity is taken to refer to other payment related comments which are summarised as follows:-

I As mentioned previously I am not ungrateful for and appreciate the ex-gratia and annual winter fuel payments which I have received.

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However the Stage 1 (£20K) and 2 (£50K) ex-gratia payments to HCV victims and survivors of this tragedy are relatively and comparatively meagre to which there is no reference in these reforms to there being any automatic increase in amount as would be appropriate and forthcoming from government as there needs to be.

Furthermore these reforms do not include for further additional automatic payments for Stage 1 HCV victims of this tragedy for which there is no reference to there being any reconciliation as there needs to be.

As has previously been referred to there is perhaps a more simple and straightforward option for these automatic payments could be considered and more appropriate if were in the form of a significantly increased one off lump sum type payment which and in the event of bereavement could be inherited by the next of kin as is in for example legal 'damages' type cases and their financial settlement.

ii There is a significant difference between ex-gratia payments made to HCV and HIV victims of this tragedy for which there is no reference in these reforms to there being any reconciliation as there needs to be.

iii There is a significant difference between ex-gratia and annual payments made to HCV Stage 1 and Stage 2 victims of this tragedy for which there is no reference in these reforms to there being any reconciliation as there needs to be.

iv There is a significant difference between charitable payments made to HCV and HIV victims of this tragedy for which there is no reference in these reforms to there being any reconciliation as there needs to be.

It is not right that victims and survivors of this tragedy should be subject to means tested, discretionary, charitable payments a most archaic, undignified and demeaning of arrangements that needs to be replaced with an alternative means of formal automatic payments.

v Apart from a winter fuel allowance Stage 1 HCV victims of this tragedy receive no other annual payment whereas HIV and Stage 2 HVC victims of this tragedy do for which there is no reference in these reforms to there being any reconciliation as there needs to be.

vi Stage 1 HCV discretionary charitable payments are means tested but these reforms do not include for them to be replaced by automatic payments to victims of this tragedy for which there is no reference to there being any reconciliation as there needs to be.

vii Apparently provisions included in these reforms for widows, dependants and children, carers, those newly infected by victims directly affected by this tragedy are not as adequate and secure as they need to be.

viii The reforms for those already bereaved and the newly bereaved should include automatic payments as a form of 'inheritance' which should be sufficient and adequate to support widows, partners, dependants etc for which a one off lump sum payment could but may not be adequate.

ix Every bleeding disorder victim infected by treatment with contaminated blood/blood products but not yet registered with an existing scheme should automatically 'qualify' for and join the scheme and receive the lump sum and other payments consistent with other such registered victims.

## 5.0 RE - 'TREATMENT'

5.1 It is obvious and should go without saying that the best of HCV (and for that matter any other) treatment should be formally advised upon, specifically funded and provided by government and offered by the NHS through specialist NHS consultants to all bleeding disorder victims and survivors of this tragedy who were treated with and infected by contaminated blood/ blood products as a matter of course and urgency and whether or not they then take up the offer is a matter for those victims and survivors to contemplate and decide upon.



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5.2 With regard to the treatment issue of blood/blood products is concerned it is beyond belief that this nation moved from a position whereby it was, rightly so, proposed I believe by David Owen, the Health Minister in the 1970's, that this nation would become self-sufficient in blood supplies to a position where it deliberately chose instead to rely upon commercial products imported into the UK from America from which of course this otherwise avoidable tragedy arose.

5.3 To make matters worse this nation has apparently also sold off a substantial share of its vitally important National blood products organisation asset to a private commercial organisation based in America from where this tragedy sprang a deal which is beyond belief and is unforgiveable.

5.4 An essential part of victims and survivors survival is to endeavour to discover and hopefully adopt both physical and psychological coping strategies in order to survive amongst which is the avoidance/minimisation of stress which these excruciating circumstances, concerns, reforms and consultation has offered no respite nor offered or done anything of worth to allay and/or avoid them.

## 6.0 RE - 'ONE SCHEME'

6.1 Initial/Interim comments have been made previously with regard to financial support and payments are referred to in the email message included under item 2.4 & 5 above since when some further comments are summarised as follows:-

6.2 Any single scheme must of course be in the interest of and victim and survivor focused and user friendly, not complex, not discriminate, simple and straightforward, be in easily understood lay terms and readily accessible, not diminish what exists or be stress/anger/anxiety inducing, complex and/or confusing.

6.3 The proposed merger of the existing organisations implies and suggests that such an arrangement would improve not only the management of the schemes but would also benefit support arrangements for victims and survivors all of which seems innocuous and sensible, however it would appear that this is not necessarily the case.

Without the benefit of appropriate professional advice or adequate in depth understanding of such things it does nevertheless appear that the proposed reform to alter from the existing to one organisation is perhaps somewhat misleading and not as innocent as it otherwise appears and needs to be.

This is especially as any such reform could perhaps in turn and in some underhand manner seem to be a devious government ploy to allow for the removal of existing financial support and alter the legal status of the existing arrangements under which they are paid and to allow such support to be lowered and/or withdrawn altogether.

6.4 There has apparently been high level government involvement with this consolidation proposal which has had a controlling but perhaps misguided hand that is without due clarity a cause of suspicion and concern which may in turn and if they knew make a one scheme consolidation unacceptable to the victims and survivors of this tragedy all of which requires urgent government clarification prior to any such decision being taken.

## 7.0 RE - 'NEXT STEPS'

7.1 As referred to elsewhere in this document I have previously requested and urged the APPG to take the necessary formal action to have these reforms and consultation withdrawn on behalf of the APPG as well as the victims, survivors and all others involved with seeking long overdue just closure to this issue to which there has been no response.

Therefore this Summary Schedule of Comments has been prepared as a response to this consultation and for government's information, perusal, and action purposes as it is obviously better and well placed with greater authority and influence to enable it to bring due just closure for the victims and survivors of this tragedy as it should and needs to do.

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7.2 As referred to under item 2.2.2 of this document successive governments in England have continually denied victims and survivors a meaningful Public Inquiry into the contaminated blood/blood products tragedy, have not cooperated to the full extent necessary in and to the process of investigation and have not been formally called upon to give evidence under oath and held fully to account.

Furthermore there have been no criminal investigations in England into the contaminated blood/blood products tragedy, there has been no legal or other action by successive governments against the manufacturers and suppliers of the contaminated blood/blood products.

These are important aspects of this tragedy which are outstanding and remain to be justly concluded.

7.3 Based upon the foregoing this government is urged and requested to urgently review and reconsider its currently inappropriate attitude towards this tragedy.

Instead and with its authority, duty, obligations, influence, moral and all other responsibilities to serve, represent and protect, as is required in this instance, respond in a manner to contribute more positively and urgently towards the due just closure for the victims and survivors of this tragedy as could, should and needs to be the case.

This opportunity offers and has the potential for government to also demonstrate, contribute towards and restore lost trust and faith in some MP's, the government, Parliament and the 'management' systems of this nation as a whole especially at this point in time when it is perhaps needed albeit belatedly but probably more than ever before especially to ensure some dignity, due and just closure to the victims and survivors of this tragedy as it should.

## 8.0 MEMORIAL

8.1 Item 1.5.3 above refers to a Memorial however the opportunity is taken to again reiterate the importance of this as there is a need for this tragedy to be formally and properly recognised by this Nation and means of a permanent memorial as an essential part of due closure to this tragedy.

GRO-B

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