

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN0381001

Exhibits: WITN0381002-9

Dated: August 2019

INFECTED BLOOD INQUIRY

EXHIBIT WITN0381005

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Expression of interest in providing evidence to the Infected Blood Inquiry

1 Your full name (if you are responding as a family member of someone Infected please also give their name):

My name is **GRO-B** and I have a direct and personal interest in and involvement with this Inquiry as being one of the haemophilia A English victims and survivors of this tragedy who was infected by treatment with contaminated blood/blood products.

In this respect this response is based upon a distillation of volumes of various other historic and more recent information, representations and responses with regard to the contaminated blood/blood products issue and this Inquiry.

2 Your contact details:

Address:

GRO-B

Email:

GRO-B

Phone/AM:

GRO-B

Your preferred way for the Inquiry to contact you:

- 1 Email
- 2 Post
- 3 Phone

3 Contact details of your lawyer (if you have one):

I note that *'You will not require a lawyer to provide evidence to the Inquiry'*.

However as far as Formal support and representation is concerned a fundamental problem that I perceive, have had and am continuing to experience is due to my being an individual haemophilia A lay person who has been issued with a public health notice with regard to CJD and infected by treatment with contaminated blood/products and is as such an integral part of but does not have the professional qualifications, expertise or experience necessary and required to adequately represent myself in this Inquiry and perhaps beyond for which I have previously and still believe needs formal suitably qualified support and assistance to do so, the problem is of course having readily available viable means of doing so.

As a consequence of this a closely associated issue of considerable concern to me is that I am not familiar or comfortable with and fully understanding the complexities and procedures involved with this Inquiry and the legal implications and considerations arising from it as I believe is necessary.

In this respect whilst now aged and exhausted by all that is associated with and has preceded this long overdue Inquiry, however I do nevertheless have some, albeit comparatively little, capacity despite which I doubt that I have sufficient and can depend and rely upon my mental agility, memory and ability to adequately engage with and respond to this Inquiry and my part in it for which I have previously and still believe needs and requires qualified support and assistance to do so.

Accordingly and in summary terms I feel compelled to note here that I have:

- i Previously referred in various representations, including for example made to the Haemophilia Society, the APPG and the DoH Infected Blood Inquiry Team with regard to the likelihood of and need for an appropriate form of personal legal representation being required prior to NHS BSA EIBSS consultation to no avail.
- ii Referred to need for legal representation in responses to the NHS BSA EIBSS consultation to no avail.

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iii Referred to need for legal representation in responses to this Inquiry thus far to no avail.

In this particular respect and for example my email messages to the Inquiry dated 09 and 28.06.18 referred again to the issue of legal/QC representation thus far to no avail in which case and for example I take the opportunity to reiterate here my comment as follows:

'Furthermore it is also of interest to see/hear from recent news that some, perhaps all, of the Grenfell victims are being personally represented at the Inquiry by a QC, however by comparison and as far as I am aware there has been no comparable formal advice or information from this Inquiry with regard to similar considerations, arrangements and provisions for the victims and survivors of this tragedy to be formally represented in such a way at this Infected Blood Inquiry about which your advice would be appreciated please.'

Reference is made above to historic representations made to The Haemophilia Society with regard to the need for legal representation which up until the informal 'second hand' news I received regarding their belated statement on 05.07.18 with regard to Williamson Law had not been forthcoming to which my message to the Inquiry dated 05.07.18 – 19.12 refers.

Following that the Haemophilia Society issued another formal message dated 11.07.18 which I did receive directly advising me of further details of this arrangement to which my letter Ref 11.02.17.hsoc22 dated 13.07.18 refers a copy of which has been forwarded previously under cover of my email message dated 14.07.18 – 15.46 an extract of which is reiterated here as follows:

'I am truly sorry to bother you again and with this, however and as referred to in my previous messages whilst I assure you that I prefer it to be otherwise and there be no such need I do nevertheless feel that it is unavoidable and I instinctively feel compelled to write in this instance with regard to two particular aspects of this Inquiry that together with others previously referred to are also causes of serious levels of most unwelcome stress, confusion and concern to me so much so that I am not at all sure about what is going on and how I should react.'

In this respect for example, with reference and further to my last message dated 11.07.18 - 15.08 and its reference to the Haemophilia Society I did coincidentally receive a message from them shortly afterwards with regard to their proposition for legal support which and as you may appreciate I was and still am unable to avoid thinking about which in turn prompted me to instinctively write my perhaps cathartic letter addressed to the Haemophilia Society Ref: 11.02.17.hsoc22 dated 13.07.18 a copy of which is attached to this message for your information and perusal.'

Furthermore whilst I have not been informed formally and/or directly I have received another item of 'second hand' news and information by which means I understand that The Haemophilia Society is in some way or another to be restricted by the Inquiry which appears to be of considerable significance to their role historically and with this Inquiry and as such is also referred to in my letter Ref 11.02.17.hsoc22 dated 13.07.18.

In this respect and as it is relevant to the current situation the content of the letter to the Society dated 13.07.18 is reiterated here as follows:

'Thank you for your message dated 11.07.18 - 15.12 with regard to legal representation at the Infected Blood Inquiry.'

In this respect on one hand I instinctively feel that given such and current circumstances it is probably best if I avoid further comment at this point in time, however and on the other hand I also feel more strongly compelled to respond to your message and invitation and I take this opportunity to do so.

Accordingly in summary terms, as variously referred to previously and bearing in mind that I am an individual long term lay person member of the Society who was infected by treatment with contaminated blood/blood products I have during the course of a considerable number of years relied, depended and called upon the Society for help and support especially towards delivering due just closure to the victims and survivors of this tragedy which is now subject to this Inquiry.

However after so long, so much and the various requests and representations that I have submitted to the Society and for example the APPG, EIBSS and more recently this Inquiry during that time regarding in particular the need for formal/legal support, advice and representation it is to say the very least most unfortunate that nothing of the sort has been forthcoming from The Haemophilia Society until now at this belated and advance stage of proceedings when I feel it is too late.

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I have little doubt that had there been a similar and timely response from the Society earlier and when it could and should have been the Societies invitation would have been welcomed by me and I expect others like me and accepted, however I now instinctively feel unable to accept this invitation especially without having the benefit of professional legal and/or advice and guidance together with adequate time to comprehend, consider and take it into account when deciding and as a matter of principal being as it is now far too late at such an advanced stage of proceedings.

This together with additional concerns which have arisen recently with regard to the Society having apparently already been in some way or another formally restricted by the Inquiry in its participation is something else which has informally emerged recently that I do not comprehend to the full extent and way necessary for me to make any decision about accepting this invitation possible at this advanced stage of proceedings, in addition to which it does appear that this legal representation has been significantly inspired by the needs of The Haemophilia Society rather than those of its members like me who also perhaps feel somewhat let down by such an unfortunate state of affairs

Accordingly I find all of this to be beyond my current capacity, experience and comprehension and thus very difficult to accommodate in the fully informed way it surely should and could have otherwise been at an earlier stage as a consequence I feel that given such circumstances I have no option other than to decline the Societies invitation.

Apart from that and being as I am a now aged long term member of The Haemophilia Society you have my continued support and appreciation for the wide ranging help and support that the Society has and continues to provide for which I and my family are most grateful and as such I confirm that I wish to remain a member of and be kept fully and appropriately informed by the Society please.'

I also take the opportunity to note that I understand that Williamson Law were involved with the Irish Inquiry of which I have no memory whatsoever, however I thought that like many others the Irish government took decisive action years ago to formally recognise and bring this issue to a form of closure which of course was not and has not been the case here and thus we are where we are today still with a long dark road ahead hoping but still not really knowing where it will take us.

As far as I am aware there have never been any proposals from government or any other authority to offer and make available to individuals like me some form of Legal aid or pro bono type legal support and representation.

As a consequence of the foregoing and there being a need whilst nothing formal has been forthcoming from the authorities and there being no readily available viable alternative to me as I had heard of their involvement I approached Collins Solicitors with regard to them representing and supporting me which they have indicated a willing ness to do and who's contact details are as follows:

Name	Collins Solicitors. SEE REVISION *Since then... IN RED TEXT BELOW
Address	20 Station Road, Watford, Hertfordshire, WD17 1AR
Phone	01923 223324
Email	amurduck@ GRO-C

However since then I received another item of 'second hand' news that also and informally come my way on the morning of 14.07.18 with regard to the Infected Blood Inquiries 'Correction Notice' dated 12.07.18 in connection with their 'Inquiry document and guidance amended and altered without authority' to which my email dated 14.07.18 – 15.46 refers an extract of which is reiterated here as follows

'In this respect and summary terms this is for me another example of my hearing of more informal 'second hand' news of an apparently significant and important aspect of this Inquiry that is as such something that readily adds to the already existing confusion and stress that I feel especially as this appears to be an issue which is contributing towards the procedures for, approach to and this Inquiry becoming more and more shambolic rather than being under control and organised as it surely must be.

Furthermore advice of what appears to be a new, significant and important issue has not come formally and directly to me from the Inquiry or elsewhere as it should as a consequence of which the implications of this apparent form of conflict requires urgent formal clarification and reconciliation between the relevant parties as at the moment it is for me at least, and perhaps others like me, adding to what is an already somewhat demanding and complex situation which I have and still do not fully comprehend to the extent necessary to make fully informed decisions and then know which way to turn and proceed with an appropriate degree of confidence.

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This is especially the case as my priority task for today was coincidentally to apply myself to the matter of how I should approach and respond to the Inquiries 'Expression of Interest in providing evidence to the Infected Blood Inquiry' form about which and given such circumstances I was and still am not at all sure or confident about how best to proceed, however despite the confusion and concerns that I have it does nevertheless seem to be prudent for me to at least meet the deadline of the 20th July for which I attach page 1 of the form so as to at least ensure that I am registered with regard to ways and means of giving evidence for which and once clear to me the remainder of the form can be completed in due course.'

However despite the proposal to complete this Eol form in due course I have nevertheless been unable to avoid the virtually constant unwelcome distracting stressful thoughts of actually doing so arising as they do and I have therefore changed my mind and completed this form as best I can given such challenging circumstances at this point in time so as to meet the deadline of the 20th and hopefully evacuate my mind of it to an extent to provide me with some welcome respite from such demands.

*Since then I attended one of the Inquiries Nationwide meetings in London on 27.07.18 following which I sent an email message to the Inquiry regarding the clarification of my 'engagement' with and proceeding further with the Inquiry which is reiterated here as follows:

From: [REDACTED] GRO-B
Date: 28/07/2018 - 13:16 (GMTDT)
To: catherine.nalty@[REDACTED] GRO-C; contact@infectedbloodinquiry.org.uk
Subject: PART 2 - IBI - Terms of Reference and Update

Dear Catherine Nalty and Infected Blood Inquiry

I write further to my earlier 10.24 message today and in particular with regard to the final paragraph in connection with the clarification of my 'engagement' with and proceeding further with the Inquiry.

In this respect and summary terms I have now written to Anna Murduck of Collins Law to which my message sent a short while ago refers as follows:

-----Original message-----

From: [REDACTED] GRO-B
Date: 28/07/2018 - 12:30 (GMTDT)
To: AMurduck@[REDACTED] GRO-C
Subject: PART 2 - (DPS:1:PI:15239:HR) Infected Blood Inquiry - [REDACTED] GRO-B

Dear Anna Murduck

I write further to my last message since when I have been unable to avoid thinking about our relationship in and this Inquiry, any part that I may have in it and in particular the approach to it considerations that I have in all honesty found to be most challenging.

In this respect summary terms and given such circumstances I feel reasonably sure that you will understand and appreciate from our previous communications that I have, to say the very least, been somewhat perplexed and anguished due to the combination of my ignorance and shortcomings especially in comprehending the what are for me the complexities associated with this Inquiry and what I perceived to be the confusing and conflicting advice with regard to ways and means of engagement and proceeding with this Inquiry and yourselves which I can no longer tolerate, allow to persist or endure.

Fundamental to this is that I had naively and incorrectly envisaged that it would be possible for me to engage directly and at the same time with both the Inquiry and Collins who would help and support me and others like me in similar circumstances with the process, however I now better understand and realise that any such 'dual' parallel type working arrangement is not possible as I had anticipated and hoped it would be.

Accordingly whilst there is for me a need for 'professional' type advice and guidance to help me I now realise that this will not be forthcoming instead of which I also understand it is my sole responsibility to decide how I wish to proceed with this Inquiry in which case and having given such circumstances my best possible consideration I rely upon my instincts, feel compelled and have decided to continue and proceed on the basis that I have previously as an individual and in this instance by engaging as best I can directly with the Inquiry and its process from now on having faith and trust that it will deliver comprehensive due just closure to the victims and survivors of this tragedy.

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Be assured that giving consideration to and reaching this decision has not been at all straightforward and I take this opportunity to apologise for any unintended inconvenience that this may have caused.

Many thanks

Regards

GRO-B

Which is considered to be self explanatory and clarifies my decision with regard to this Inquiry and proceeding with it.

Accordingly I attach my 'Expression of Interest in providing evidence to the Infected Blood Inquiry' form Ref 11.02.20.5.ibi.6 dated 15.07.18 which was sent to Collins Law previously u/c of my email message dated 15.07.18 - 16.39 for them to forward on to yourselves, however whilst requested I have received no such confirmation to date that it actually was.

In view of this the attached 'Eoi' form should be read together and in conjunction with this message with particular regard to my decision and the response to Item 3 'Contact details of you lawyer (if you have one) which should now omit reference to Collins Law and their contact details please.

Many thanks, Regards: GRO-B

4 Summary of your evidence:

When and where were you or your family member infected?

It is obviously not possible for me to be absolutely precise about these details, however in my case it would have been between the early 1970's around 1972 - 73 when I was a patient at Kings College Hospital and Oxford Haemophilia Centre, factor VIII concentrates became available and I received treatment with them up until the time which I am unable to accurately recall or be sure about say around mid-1980's? when alternative, probably heat treated, concentrate Factor VIII treatments became available and were then used.

How were you or your family member infected?

I was infected by treatment for haemophilia A related reasons with contaminated blood/blood products.

Please tell us whether you or your family member receive(d) any financial support and if so the name of the Trust or Scheme. Please also tell us if you or your family member applied for support and were refused.

I am known to and have received financial support from Skipton/Caxton Fund and NHS BSA EIBSS.

If you have documents that you wish to provide as evidence, such as medical records, please indicate the type of documents and the number of pages. Please do not submit any documents at this stage.

As far as my health record is concerned I feel that in my particular case and for the purposes of this Inquiry and without wishing to appear in any way flippant what needs to be known is known in so far as I am a person with haemophilia A known to Skipton, Caxton, EIBSS and this Inquiry who has been issued with a public health notice with regard to CJD and was infected by treatment with contaminated blood which and in addition to the burden, blight and hindrance of being a haemophiliac had a devastating impact upon my own life as well as an adverse detrimental impact upon the lives of other people close to me beyond which I am currently unable to see or comprehend the need for more nor do I want to be or make such sensitive personal private and confidential health record information public.

I have enquired about my medical records previously and whilst some were provided and for example include reference to treatment with concentrates others were not as at the time of my enquiry I was advised that they had been destroyed, however since then I have been given to understand that they were found but I have not requested or seen them.

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5 Providing your evidence:

Would you be willing to provide a written statement to the Inquiry? Are there aspects of your evidence that you would want to remain private?

Yes and if it is absolutely necessary for me to do so - However I note from the Inquiries email message dated 02.07.18 that *'You should feel under no obligation to share your experience but we anticipate that many of you will want to do this'*.

This is a most thoughtful opportunity which I understand, welcome and appreciate with thanks, however for me at least this Inquiry is also the latest amongst a number other routine and 'milestone' type events which have preceded it that also serves and acts as painful reminder of this issue and are added to our constant daily thoughts arising from this tragedy of which I for one have not and whilst alive am unlikely to ever be free and at peace.

However and in summary terms this from of 'sharing' is an aspect of this Inquiry that together with considerations with regard to the prospect of being a core participant, providing evidence and/or providing details of my health records which I have been churning and mulling over and over are causes of stress, difficulty and concern to me.

As a consequence of this I instinctively feel inclined to avoid doing so as I feel uncomfortable with the prospects and potential for 'fall out' arising from it in addition to which I am in the context of this Inquiry and by some miracle a retired somewhat private introverted GRO-B individual who keeps to himself is exhausted by all that has preceded this and does not have the inclination, capacity and full range of personal abilities, emotional strength and composure, mental agility and memory readily available to confidently process and engage as an individual in a full and proper way as I believe to be necessary.

I hope that it's not but I do realise that this may in some way or another be problematic and if it is I need to be advised accordingly so as to give such things further consideration, however and in the meantime having mentioned such things here it has helped me to note in an albeit brief and cathartic manner some current thoughts on these considerations that may in turn also provide you with some indication of my current point of view going forward.

In the meantime I take the opportunity to refer to my email message to the Inquiry dated 01.08.18 – 09.43 as follows:

'I am sorry to bother you but having been prompted by your message yesterday I have been unable to avoid thinking about it as a consequence of which feel compelled to share what is for me a cathartic 'thought' with you and the Inquiry.

In this respect and summary terms be assured that I have continually endeavoured and wish to cooperate and proceed with this as best I can, however I believe that whilst we may have a part to play it is not so much the 'exhausted' victims and survivors of this tragedy and their plight that require scrutiny it is the circumstances, reasons for which and those responsible and accountable for it that do. Regards **GRO-B**

Some people who have provided a written statement will be asked to give evidence at a public hearing. Would you be interested in giving evidence at a public hearing (the Inquiry will pay reasonable expenses of attending a hearing to give evidence)?

In view of the foregoing responses I prefer not to appear and give evidence at a public hearing in person, however I wish to reserve and retain the right to contribute, express my point of view and opinion as may be necessary preferably in some other suitably private, confidential and anonymous way.

The Inquiry is considering how people who do not want to provide a written statement could give their evidence: for instance by sharing their experience with a trained professional who would submit a report covering a number of people's experiences. Would you be interested in an approach like this?

Yes.

Having previously replied 'Yes' to this particular question on the Inquiries Eol form rather than new my initial and further response has been based upon previous comments and information provided for other such purposes previously which is summarised as follows:

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1 In summary terms I as mentioned before I have and continue to suffer from mental health issues depression, anxiety, anguish, stress and have poor sleep the misery of which I have no doubt or hesitation whatsoever is significantly and substantially attributable and due to having been infected with contaminated blood and the debilitating traumatic adverse detrimental and exhausting impact of adapting, coping and learning to live with it which has and continues to affect not only my daily living but also my life as a whole with which I do thankfully also receive support from my wife.

2 I have in the past and still routinely feel generally unwell, fatigued both physically and mentally and suffer from what I believe to be SAD, the 'spark' I once in life had has long since gone, I am withdrawn, feel vulnerable and exposed, I avoid socialising and taking on new and/or demanding commitments, I find it difficult being away from home, walking as item 5.2 and get by in as simple manner as is possible on slow and steady one step at a time day to day basis minimising and/or avoiding as far as possible potentially depressing stress inducing situations difficult to contend with to have some capacity for what cannot be avoided such as this.

3 My mind, and memory are falling as they frequently seem to be in some way impaired and there are gaps where such information used to be, my focus and concentration is poor, mental agility is slowing and there is at times a sense of vagueness, difficulty with decisions about things, quality sleep is difficult to come by, nights are always restless, mornings always a challenge and days which follow are similar.

4 However whilst there is difficulty I do when able endeavour, but it is not always possible, to carry out simple 'daily activities' to which the form refers ie leaving home, although greatly reduced driving for the convenience it affords us and occasionally using public transport or shopping for essentials although not always easily and on routine daily basis.

5 I have struggled previously and again now with and pondered at length upon how to respond to this process and concluded that rather than new I depend instead upon some of the wider ranging comments submitted previously to the IBRT both prior to and subsequently in response to the Infected Blood Consultation (Ref 11.02.20.1.1 dated 13.04.16) as they have relevance to this Inquiry and in particular item 6 – **2.0 IMPACT STATEMENT** which is therefore reiterated here as follows:

'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.'*

6 GENERAL HEALTH

6.1 For overall background purposes and as far as my general health is concerned Haemophilia A and having been infected with contaminated blood aside I suffer from a number of other physical conditions eg Osteo Arthritis, Sciatica, Lower back problems, Gout, Tendonitis, Hypertension, palpitations and 'dry coughing' type spasms, Prostrate, Tinnitus, 'Digestive' /IBS type problems etc some of which have and continue to be a cause of chronic pain and discomfort that has an exhausting adverse detrimental impact upon and constantly restricts my walking, mobility and ability to normally carry out daily activities with which I do thankfully receive support from my wife.

In this respect and as far as I am aware I have not been formally advised that these physical conditions have been caused or made worse by having been infected with contaminated blood.

6.2 As I believe it has some particular relevance I take the opportunity to mention here that leisure time casual type activities such as angling and walking, especially in the countryside or at the seaside beaches and pathways, was once a significant therapeutic part of our life and the considerable restriction and loss that it represents is now greatly missed.

7.0 DATE OF DIAGNOSIS

Having been prompted by hearing of others being asked and thoughts arising with regard to my receiving a formal diagnosis I recall that this question has been raised before which in my case and as far as I have been able to determine it was probably at an appointment I had with Dr Charles Rizza at the Oxford Haemophilia Centre on 18.06.1991 and was subsequently discussed between us at an appointment arranged to do so on 10.09.91.

In this respect summary terms and for example I wrote to Dr Paul Giangrande – Consultant Haematologist at OHC on 08.08.2004 with regard to my medical records and specific questions including clarification of the date I was formally diagnosed and I have had sight of my OHC medical records. (My ref to Archer Inquiry file)

However whilst there are some 'typical' documents on my file which refer to a diagnosis there is no clear or specific record on the file of the actual date and means by which I was informed in addition to which there is no specific record of my GP having been advised in the normal routine manner such things are which caused me to wonder at the time if my OHC records are as intact and complete as they should be about which I sought further advice to no avail.

What I do have are some notes of treatment with concentrate factor VIII and a chart record of my blood tests which appears to give an indication of when the infection was confirmed.

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6. Please use this space to provide any additional information.

In this respect and as requested I take this opportunity to refer to my email addressed to the Inquiry dated 18.03.18 – 14.48 and the attached letter Ref 11.02.20.5.ibi.1 dated 18.03.18 and document entitled:

DoH PROPOSALS TO REFORM THE INFECTED BLOOD PAYMENT SCHEME – January 2016
SUMMARY SCHEDULE OF COMMENTS IN RESPONSE TO CONSULTATION - SHEET 2 of 15

Ref:- 11.02.20.1.1
13.04.16

As referred to in that initial email message and all other communications between us since which are relevant to this question.

In addition I also take this opportunity to summarise my further comments as follows:

In this respect this response has been based upon a distillation of volumes of other such historic and more current information and responses and is as such summarised as follows:

1.0 INQUIRY DEADLINE of the 20th July 2018 FOR RESPONSES

I have now given the Inquiries message dated 02.07.18 it's 5 attachments and my response to them some consideration, however I refer for example to my email messages to the Inquiry dated 05.07.18 – 19.12 and 06.07.18 – 00.07 and other such subsequent messages with regard to and prompted by the new, most distracting 'second hand' items of information and news of Haemophilia Societies statement regarding Williamson Law and coming as belatedly as it does at such an advanced stage in the proceedings the potentially serious implications of it.

In this respect and as referred to in my messages I reiterate here that in my opinion and given such circumstances the deadline for the 20th does not allow sufficient time and opportunity for lay individuals like me and perhaps others in similar circumstances to properly consider, comprehend and respond to the Inquiry to the extent and fully informed manner as is necessary.

The news of The Haemophilia Societies statement coming at such an advance stage of proceedings is a major distraction at this already most stressful and demanding time, it is also a significantly important development especially given the history prior to and the current circumstances of the Inquiry and the deadline of the 20th for lay persons like me to properly comprehend and respond all of which is as such a considerable cause of concern to me about which I have been compelled to directly seek the intervention, help and guidance of the Inquiry team.

This is especially the case in so far as despite such suggestions and after so many years of there being no such formal support and this issue barely moving at a slower than glacial pace there is a now a burst of activity amongst and not least of which is my own and perhaps others need to comprehend and decide upon how best to respond to the Inquiry by the deadline date of the 20th of July which I for one am finding to be most stressful and demanding to do so much so that I think it is unlikely that I will be able to do so in the way that appears to be required and necessary.

A fundamental part of the problem for me and perhaps others like me is being already unwell and exhausted by years of involvement with the contaminated blood issue and now in contrast and like other historic instances the impact of this Inquiry and comparably sudden deadline of the 20th all of which is daunting, complex, makes me feel more unwell and in my opinion leaves relatively little and inadequate time for me and perhaps others like me to properly consider, discuss, seek advice and clarification and make fully informed decisions upon such issues about which and together with items of associated new news that seem to arise to distract us as referred to in my messages to the Inquiry.

Accordingly I respectfully urge and request the Inquiry to give due consideration to this representation and these matters and in turn provide further due guidance and if necessary extension of time to the 20th deadline to suit please.

2.0 REGISTRATION

At one point in this process the question of whether or not I was registered with the Inquiry cropped up which in turn prompted my email message dated 28.06.18 – 11.40 to Inquiry as follows:

'I am sorry to bother you, however I do nevertheless feel compelled to write having been prompted by hearing reference recently to individual people like me being 'registered directly' with the Inquiry and other Inquiry related issues that and as a lay person I am not but feel the need to be fully familiar with.

ANONYMOUS

In this respect and summary terms I take it for granted that I am formally, fully and appropriately 'registered directly' with the Inquiry and that the Inquiry will keep me directly, personally formally, fully and appropriately informed as and when it is necessary to do so about which I request the Inquiries advice and clarification please.'

I have not received a response to this, however as I subsequently received an email message dated 02.07.18 together with its 5 attachments from the Inquiry I am reassured that I am 'registered directly' with the Inquiry, however should that not be the case please advise me so as to ensure that it is rectified as a matter of urgency and without further ado please.

3.0 COMMUNICATIONS

I am not convinced that they are yet as they need to be and as the need for good communications between all parties is obviously of vital importance I take this opportunity to refer for example in my email message to the Inquiry dated 25.06.18 – 17.15 which are reiterated here as follows:

'As previously mentioned I am not involved with social media but I know someone is who occasionally passes some items of information onto me as was the case in this instance, hence my reference to and use of 'second-hand news' terminology.

In this respect your assumption is incorrect and since you ask I am an 'individual' as it were 'working' independently alone and a long term member of the Haemophilia Society and apart from that I have not been and am not involved with or a member of any of the campaigning groups of which there now seem to be many and for me to many and too much to be able to keep up with.'

Furthermore whilst I am a long term member of The Haemophilia Society I do not have the capacity and am not able and do not routinely monitor theirs, the Inquiries or any of the multitude of other 'campaign' and other associated websites which now exist nor do I have the capacity and ability to routinely process emails daily and the high volume of information which seems to abound.

As such it is obviously not right, prudent or possible for me to depend upon 'second - hand news' and I rely instead upon hearing directly from the Inquiry as per message to Inquiry dated 28.06.18 as follows:

'In this respect and summary terms I take it for granted that I am formally, fully and appropriately 'registered directly' with the Inquiry and that the Inquiry will keep me directly, personally formally, fully and appropriately informed as and when it is necessary to do so about which I request the Inquiries advice and clarification please.'

To which there has been no response, however being a member and for the same reasons I have also advised The Haemophilia Society in a similar way in addition to which I have also been given to understand that now the Inquiry is underway there are formal procedures with regard to communications between myself, the Inquiry and Collins Solicitors which at the moment I do not in all honesty fully comprehend but any such communications between us will need to be dealt with in the same specific and direct way.

For example reference was made to communications in my email dated 04.05.18 – 10.31 an extract of which is reiterated here as follows;

'In the meantime and in summary terms please note that I have written to The Haemophilia Society along similar lines in so far as I do understand that the matter of 'mass' communication involving many widely dispersed people upon a somewhat demanding, sensitive and complex issue that is continually evolving such as this is very challenging.

I do appreciate that 'social media' is very popular, and is perhaps, dependent upon the particular circumstances, a convenient day to day means of communication and is used in such circumstances to 'informally' spread the word, get some idea and gauge the reaction to and temperature of such issues, however and as mentioned previously not all of us are involved with social media or computers/emails and with more Formal issues such as this Public Inquiry there comes a point where a Formal approach is necessary especially when important issues arise and those involved with them need to be included and appropriately, adequately and properly informed about them.

In my case I do use email but am not 'tech savvy' or in any way involved with 'social media' in which case 'Traditionally' letters, latterly email serve a particular purpose and in instances such as this where a number of people need to be kept up to date with new 'news' and 'developments' that directly impact upon and involve them it occurs to me that a specific 'on demand' type 'News letter' approach including prompts and guidance as necessary may help towards covering all bases and means of communication.'

ANONYMOUS

4.0 NATIONWIDE MEETINGS

I acknowledge with thanks and appreciation that the Inquiry has arranged for nationwide meetings to take place between the Inquiry team and individuals like me who are in one way or another directly involved with and are part of this Inquiry.

In this respect I have received notifications of such meetings to which I have responded, however I have not yet and for reasons given been able to attend one of these meetings.

In the meantime as referred to in my message to the Inquiry dated 28.06.18 – 11.40 and as far as I understand it some individuals have apparently been involved with 'formal' meetings with the Inquiry about which I am somewhat concerned as some of those individuals involved may have had some influence but do not have my 'authority' to act on my behalf and as such do not necessarily represent me or my point of view that could amount to a form of unfair advantage.

However as there has been no response I remain somewhat concerned as the format of and agenda for the nationwide meetings between the Inquiry and individual people like me may not be the same nor have any such and/or the same degree of influence as the 'formal' meetings which took place previously and perhaps since and which may be ongoing.

As referred to under item '3 Contact details of your lawyer (if you have one)' above having attended one of the Inquiries Nationwide meetings in London on 27.07.18 to which my email dated 28.07.18 to the Inquiry refers.

5.0 TERMS OF REFERENCE

I have from my inexperienced layperson point of view previously submitted various representations to the Inquiry including those in connection with the Inquiries Terms of Reference consultation which have now been finalised, distributed and of which I have a copy, however I have not received any other response to my submissions and as a layperson without the benefit of professional advice and interpretation I am unable to reconcile the two which is a cause of concern to me.

In this respect and for example my letter Ref 11.02.20.5.ibi.3 dated 01.04.18 to the Inquiry refers to the issue of treatment centres an extract from which is reiterated here as follows:

'Whilst such things are on my mind I feel compelled to do so and now write further to my previous responses to this consultation about the Inquiries Terms of Reference.

In this respect whilst reference is already a part of my initial response to this consultation, in my Doc ref 11.02.20.1.1, item 5, para 4, I nevertheless take this opportunity to mention again here so as to reinforce a particular issue of utmost concern to me and no doubt other bleeding disorder patients and their families who find themselves in similar circumstances aspects of which are summarised as follows:

'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.'

Accordingly I respectfully request that this issue be included as a further and particular part of my response to this consultation please.'

ANONYMOUS

6.0 COMMENCEMENT OF INQUIRY

After so many years despite the bad news associated with an Inquiry being so shamefully long overdue by so many years it is some welcome good news that this one has at long last now commenced.

Having progressed at a less than glacial pace it is worthy of note that we are now being required to step up and move at a relatively high speed which is understandable but I for one have long since been and am exhausted by the circumstances that have preceded the commencement of this Inquiry.

7.0 GATHERING OF EVIDENCE

I confess that I am not in all honesty sure if this gathering of evidence and providing it to the Inquiry applies to me or not in so far as I have already provided various representations to the Inquiry and without guidance I currently feel that there nothing to add to what I have already provided to the Inquiry about which your further advice and guidance is requested please.

I cannot avoid referring to the task of 'gathering of evidence' especially from the authorities who despite everything have not thus far cooperated in any such way that has significantly contributed towards a deliberate 'cover up' all of which are vitally important aspects of this issue and Inquiry into it to which I have made reference in my various representations to others prior to and subsequently to this Inquiry an extract of which is for example as follows:

**'DoH PROPOSALS TO REFORM THE INFECTED BLOOD PAYMENT SCHEME – January 2016
SUMMARY SCHEDULE OF COMMENTS IN RESPONSE TO CONSULTATION - SHEET 4 of 15**

**Ref:- 11.02.20.1.1
13.04.16**

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.

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.'

ANONYMOUS

Expression of Interest In providing evidence to the Infected Blood Inquiry - Sheet 13 of 17

Ref: 11.02.20.5.IBI.6.Rev A

This Inquiry must leave no stone unturned in getting to the bottom of this issue, uncovering any 'cover up' and exposing the truth, ensuring that those who may need to be are called to full and proper account and that further actions which may then arise are promptly taken towards delivering due and just closure to the victims and survivors of this tragedy.

8.0 SHARE YOUR EXPERIENCE – PUBLIC HEARING

I note from the Inquiries email message dated 02.07.18 that *'You should feel under no obligation to share your experience but we anticipate that many of you will want to do this'*.

This is a most thoughtful opportunity which I understand, welcome and appreciate with thanks, however for me at least this Inquiry is also the latest amongst a number other routine and 'milestone' type events which have preceded it that also serves and acts as painful reminder of this issue and are added to our constant daily thoughts arising from this tragedy of which I for one have not and whilst alive am unlikely to ever be free and at peace.

However and in summary terms this from of 'sharing' is an aspect of this Inquiry that together with considerations with regard to the prospect of being a core participant, providing evidence and/or providing details of my health records which I have been churning and mulling over and over are causes of stress, difficulty and concern to me.

As a consequence of this I instinctively feel inclined to avoid doing so as I feel uncomfortable with the prospects and potential for 'fall out' arising from it in addition to which I am in the context of this Inquiry and by some miracle a retired somewhat private introverted 73yoa individual who keeps to himself is exhausted by all that has preceded this and does not have the inclination, capacity and full range of personal abilities, emotional strength and composure, mental agility and memory readily available to confidently process and engage as an individual in a full and proper way as I believe to be necessary.

However despite my concerns and reluctance should a need arise and for some reason it becomes absolutely necessary I should be made aware of the circumstances in order that I can then understand and reconsider my position.

As far as my health record is concerned I feel that in my particular case and for the purposes of this Inquiry and without wishing to appear in any way flippant what needs to be known is known in so far as I am a person with haemophilia A known to the Society, APPG, Skipton, Caxton, NHS IBI Team, EIBSS etc and this Inquiry who has been issued with a public health notice with regard to CJD and was infected by treatment with contaminated blood which and in addition to the burden, blight and hindrance of being a haemophiliac had a devastating impact upon my own life as well as an adverse detrimental impact upon the lives of other people close to me beyond which I am currently unable to see or comprehend the need for more nor do I want to be or make such sensitive personal private and confidential health record information public.

I have enquired about my medical records previously and whilst some were provided others were not as I was advised that they had been destroyed since when I understand that they were found but I have not requested or seen them.

I hope that it's not but I do realise that this may in some way or another be problematic and if it is I need to be advised accordingly so as to give such things further consideration, however and in the meantime having mentioned such things here it has helped me to note in an albeit brief and cathartic manner some current thoughts on these considerations that may in turn also provide you with some indication of my current point of view going forward.

9.0 CORE PARTICIPANTS

Reference is made above under item 9.0 to the matter of 'Core Participants' and under item 5.0 to individuals participation with Nationwide and other such meetings beforehand.

In this respect reference is also made to my email message to the Inquiry dated 28.06.18 – 11.40 which was in part prompted by hearing the terminology 'core participants' the definition and implications of which were not then and are still not as clear to me as it needs to be.

In this respect and as referred to under item 9.0 above the personal problem that I have is that whilst I am reluctant and uncomfortable with publically identifying myself if necessary I would like to think that if necessary there are alternative ways and means available by which my point of view and opinion will in some way or another be heard especially in the event that important considerations arise that require decisions to be made about issues that would have a direct affect upon me.

ANONYMOUS

10.0 INQUIRY OPENING 'EVENT' AND MEMORIAL

I realise that this may not be relevant to this particular part of the proceedings, however in view of item 10.0 above I cannot avoid making reference here to my message to the Inquiry dated 25.06.18 – 16.45 with regard to an Opening Event and Memorial which is reiterated here as follows:

'Dear Infected Blood Inquiry

Whilst I prefer there to be no such need or reason I do nevertheless feel compelled to write having been prompted once again by rather than formally hearing recently of some informal 'second-hand news' circulating in connection with this Inquiry.

In this respect summary terms and as mentioned previously I am not involved with so called 'social media', however as far as I understand it the Inquiry is apparently programmed to commence on 24.09.18 and that it is proposed to mark the occasion with an 'event' for which individuals thoughts and ideas are being sought as a consequence of which those that have occurred to me are summarised as follows:

I am personally in no doubt and believe that any such 'event' should and needs to be most dignified, sensitive and solemn and be arranged to take place as soon as possible at the front end of the Inquiry proceedings in order to serve to remind, remember, acknowledge and provide what I believe should be in the form of a memorable visual image to represent each of the victims and survivors of this tragedy, the loss and impact of it and the fundamental reason for this long overdue Inquiry.

I confess that whilst I believe that it is possible I am not sure how to achieve such an 'image' in the way I visualise it, which is that each of the victims and survivors of this tragedy are represented by the same number of people all simply and identically dressed quietly entering the Inquiry room once those present have settled down, perhaps to duly solemn and discrete background music, ideally along an aisle on one side of the room, all carrying before them a simple symbol for each, which is carefully placed upon a visible glass table like display to be left in front of the Inquiry bench for its duration, and after a bow of the head then leaving along an aisle on the opposite side of the room to assemble and form a human version of the symbol outside whilst a dedicated two minute silence is observed.

Following the Inquiry the symbols, perhaps similar to poppy day in the form of a simple memorial cross or other shape, could then be transferred to an appropriate public place pending and where the permanent Memorial to the victims and survivors of this tragedy is to be located to not only to remember them and this tragedy but also become a place to visit, contemplate and place memorial symbols in the future perhaps annually on a day specifically identified by the Inquiry for such purposes.

Whilst writing and as far as a Memorial is concerned I take this opportunity to mention again here that I have referred to this in representations previously submitted to the Inquiry and various other parties beforehand an extract of which is for example as follows:

'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 to government (Parliament Square perhaps?) to mark the 'worst tragedy in the history of the NHS' that would be an appropriate gesture to all it's 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.

This memorial needs to be something very significant in a very public place and definitely not be tucked away in a remote corner somewhere where few will see and be reminded of it, in any event those who may already be involved will hopefully be open minded to suggestions about what, where and how to deliver a fitting memorial and in some way or another obliged to engage with others about it which would I think be a good opportunity for delivering a great piece by a great artist/designer perhaps by means of competition.'

Which I hope and trust will be taken as a contribution that will of some interest to and form part of the Inquiry's deliberations and conclusion of this Inquiry.

ANONYMOUS

Expression of interest in providing evidence to the Infected Blood Inquiry - Sheet 15 of 17

Ref: 11.02.20.5.IBI.6.Rev A

11.0 INQUIRY OPENING 'SPEAKERS'

I realise that this may not be the time but it is an opportunity that I cannot miss to mention that amongst all of the other examples of 'second hand' news that I have heard one recently was of the likelihood that important 'big name' people are being considered to speak at the opening of the Inquiry which in principle is not unreasonable and understandable, however one of the names mentioned is that of Andy Burnham.

In this respect whilst I acknowledge that his valedictory type speech and comments to mark the end of his time in the House definitely contributed towards the announcement of this Inquiry I nevertheless have reservations about him and speaking here and on such an occasion.

In summary terms whilst he deserves due credit for his albeit belatedly intervention my reasons for this are whilst my memory is not what was or I would like it to be I still have some including one which I am fairly sure is reasonably accurate and recall from one of the broadcasts from the House I saw when the contaminated blood issues was under debate.

This particular debate took place at a time when Andy Burnham was in government and had held senior positions as Minister and/or Secretary of State for Health despite which I recall that when involved with the debate he acted 'dumb' and denied having any or little awareness of the contaminated blood issue by which I was so astonished and infuriated that it left its mark with the help of considerable disbelief that someone in such a position should react in such a casually dismissive way.

Not so very long afterwards his valedictory was by comparison a well-informed and significant change of course which was convincing but I found difficult to absorb for such earlier dismissive and subsequent 'on the shoulders of others' and 'jumping on the bandwagon' type reasons which deserves no credit and I believe to be sufficient to prevent him speaking on this occasion.

If it transpires that my memory and recollection has failed me and I am wrong I apologise unreservedly and withdraw any such reservations.

12.0 'MAXWELLISATION'

In the midst of others yet another item of 'second hand' news informally came my way on 11.07.18 with regard to the term 'Maxwellisation'.

In this respect I have no idea what 'Maxwellisation' means but with the name Maxwell in it, vague memories of its notoriety years ago and as far as I understand it in the context of this Inquiry it is apparently a term that has significant potential to seriously disrupt this Inquiry which does of course need to be avoided.

Apparently and as far as I understand it 'Maxwellisation' is something that only the Inquiry can decide about which appears to be a 'no brainer' nevertheless that is not in my experience something that can be relied upon.

I take that as I have become aware of this others in authority and with responsibility and influence over such issues will be too and will as such be taking urgent and appropriate action in order to clarify this issue and to also ensure that it has no disruptive impact upon this Inquiry whatsoever.

13.0 IBI ENVELOPE POST MARKING

I take this opportunity to note that an item of post that I received recently from the Inquiry had a marking that clearly identified that it was from the Infected Blood Inquiry by which I was and still am concerned about for fundamental confidentiality and perhaps other data protection reasons, however despite my concerns I did not contact the Inquiry about it and I do so now by virtue of this comment in the hope that any such IBI envelope marking will be avoided in the future please.

14.0 HOLBY CITY

Please note that I did write a message dated 04.05.18 – 10.31 to the Inquiry in order to express my concerns arising from the BBC's Holby City commencement of a HCV related story line and the sensitive delicate nature of it starting at more or less the time of this Inquiry, however I received no response to my message and I had in all honesty forgotten about it as I avoid watching Holby and being preoccupied and in the midst of all other things involved with this Inquiry, nevertheless I still consider my comments to be valid.

ANONYMOUS

Expression of Interest in providing evidence to the Infected Blood Inquiry - Sheet 16 of 17

Ref: 11.02.20.5.lbi.6.Rev A

Whilst writing I take the opportunity to include some additional items which have occurred to me since submitting my Eol form dated 15.07.18 as follows:

15.0 UKHCDO

Another item of informal 'second hand' news that came my way was with regard to the involvement of UKHCDO and their role, relationship and association with the contaminated blood issue.

In this respect I am aware of UKHCDO and that a 'lot' of NHS doctors and other staff have/are in some way involved with it and as such it appeared to me to be entirely 'innocent' and not unreasonable for it to exist as some form of centralised umbrella organisation about which it did not occur to me that there should be and I have not had any particular concerns about UKHCDO.

I have written to UKHCDO, copied to others, on several occasions in the past in particular to 'complain' about the closure of so many haemophilia care centres to which I received no response whatsoever which was disappointing but not unusual when trying to deal with those in some sort of authority and I gave up.

However what I did not appreciate was that UKHCDO is a 'private organisation' and as such I have no idea what the implications of that are, **however I have no recollection about being formally made aware, being specifically asked about or formally agreeing to my medical records being sent to UKHCDO** and on that basis it would have not surprised me if they had for innocent 'bigger picture' type research purposes that now appears to be a perhaps somewhat naïve trust based point of view in the midst of all that is now being stirred up by the Inquiry.

Accordingly the role, involvement and responsibilities of UKHCDO needs to be clarified by this Inquiry.

16.0 INQUIRY COMMENCEMENT AND COMMEMORATION

Another item of informal 'second hand' news that came my way was to do with these consideration to which my email message dated 25.06.18 – 16.15 to the Inquiry refers as follows:

'Whilst I prefer there to be no such need or reason I do nevertheless feel compelled to write having been prompted once again by rather than formally hearing recently of some informal 'second-hand news' circulating in connection with this Inquiry.

In this respect summary terms and as mentioned previously I am not involved with so called 'social media', however as far as I understand it the Inquiry is apparently programmed to commence on 24.09.18 and that it is proposed to mark the occasion with an 'event' for which individuals thoughts and ideas are being sought as a consequence of which those that have occurred to me are summarised as follows:

I am personally in no doubt and believe that any such 'event' should and needs to be most dignified, sensitive and solemn and be arranged to take place as soon as possible at the front end of the Inquiry proceedings in order to serve to remind, remember, acknowledge and provide what I believe should be in the form of a memorable visual image to represent each of the victims and survivors of this tragedy, the loss and impact of it and the fundamental reason for this long overdue Inquiry.

I confess that whilst I believe that it is possible I am not sure how to achieve such an 'image' in the way I visualise it, which is that each of the victims and survivors of this tragedy are represented by the same number of people all simply and identically dressed quietly entering the Inquiry room once those present have settled down, perhaps to duly solemn and discrete background music, ideally along an aisle on one side of the room, all carrying before them a simple symbol for each, which is carefully placed upon a visible glass table like display to be left in front of the Inquiry bench for its duration, and after a bow of the head then leaving along an aisle on the opposite side of the room to assemble and form a human version of the symbol outside whilst a dedicated two minute silence is observed.

Following the Inquiry the symbols, perhaps similar to poppy day in the form of a simple memorial cross or other shape, could then be transferred to an appropriate public place pending and where the permanent Memorial to the victims and survivors of this tragedy is to be located to not only to remember them and this tragedy but also become a place to visit, contemplate and place memorial symbols in the future perhaps annually on a day specifically identified by the Inquiry for such purposes.

ANONYMOUS

Expression of Interest In providing evidence to the Infected Blood Inquiry - Sheet 17 of 17

Ref: 11.02.20.5.ibi.6.Rev A

Whilst writing and as far as a Memorial is concerned I take this opportunity to mention again here that I have referred to this in representations previously submitted to the Inquiry and various other parties beforehand an extract of which is for example as follows:

'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 to government (Parliament Square perhaps?) to mark the 'worst tragedy in the history of the NHS' that would be an appropriate gesture to all it's 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.

This memorial needs to be something very significant in a very public place and definitely not be tucked away in a remote corner somewhere where few will see and be reminded of it, in any event those who may already be involved will hopefully be open minded to suggestions about what, where and how to deliver a fitting memorial and in some way or another obliged to engage with others about it which would I think be a good opportunity for delivering a great piece by a great artist/designer perhaps by means of competition.

I have an interest in and have had some further thoughts with regard to a Memorial which I feel compelled and would like to share with the Inquiry and others involved with it.

17.0 COMMUNICATIONS

I confess that these have for me been somewhat overwhelming circumstances by which I am even more exhausted, stressed and feeling more unwell than I already was by all and the years that have preceded this Inquiry and I am in all honesty still somewhat uncomfortable and confused by such circumstances not made any easier by what is for me the complexity, time restraints and the various parties being remote, distant and at arm's length from one another whilst at the same time trying to deal with communications and process such complicated matters which will hopefully improve.

GRO-B

Date: 15.07.18

Date: 06.08.18 - Revision A

Ref: 11.02.20.5.ibi.6.Rev A = Revisions indicated by red text