Witness Name: The Scottish Infected Blood Forum
Statement No.: WITN7165001
Exhibits: WITN7165002-015
Dated: 10th August 2022

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF THE SCOTTISH INFECTED BLOOD FORUM

We provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 17 June 2022.

I, Joyce Donnelly, GRO-A and Thomas Leggate, will say as follows: -

Section 1. Introduction

Please state your names, addresses and dates of birth.

Please explain your role within the Scottish Infected Blood Forum ("SIBF"), including your responsibility within this role.

1. My name is GRO-A, my date of birth is GRO-A 1962, and my address is known to the Inquiry. I am a founding member of the SIBF and have been a part of its work since the charity's inception in October of 2012. I played a leading role in the formation of the charity and its registration with the Office of the Scottish Charity Regulator (OSCR) in 2012, in part due to my experience in the voluntary sector. As required during the first year or so before and after the organisation was formally registered, I variously "covered"

the roles of Vice-Convener, Treasurer, and Secretary until the membership was established, sufficient that there were others who were able to take on these Executive roles on the Management Committee.

2. My responsibilities as Vice-Convenor involved acting as a Deputy to the Convenor as required, Chairing Management Committee Sub-Groups as required and acting as an authorised and named cheque signatory for the organisation. As Treasurer, I took responsibility for monitoring the financial transactions of the SIBF, making payments on behalf of the organisation, receiving, reconciling and filing bank statements, acting as a named cheque signatory, providing quarterly financial reports to the Management Committee and annual financial reports to our membership at Annual General Meetings, providing support to appointed auditors or independent examiners as required and contributing financial accounting information to the Annual Report and Annual Return in accordance with relevant legal requirements. As Secretary of the SIBF, my responsibilities included receiving and responding to correspondence, acting as a named cheque signatory, ensuring minutes of meetings were accurate, approved, and filed correctly, maintaining membership records in accordance with relevant data protection requirements and overseeing the SIBF's Annual General Meetings.

3. As well as these formal Executive roles, I provided direct secretarial support to the Founding Convenor and more recently I have acted as an Advisor to the Management Committee. I have also served as an independent consultant contracted to deliver bespoke project work for the SIBF. Mostly, I carry out pro-bono consultant activities on behalf of the organisation, with the occasional small piece of contracted work to deliver bespoke project actions when grant funds are allocated for those tasks. These paid projects have included me being involved in the design, facilitation, and analysis of membership surveys, the production of volunteering development good practice resources as well the production of administrative resources such as volunteer expense claim forms. After my more formal involvement with the SIBF Management Committee in its beginnings, I stepped back to encourage others to be more actively involved while I became an ordinary member of the organisation.

4. My name is Catherine Joyce Donnelly, my date of birth is GRO-C 1937, and my address is known to the Inquiry. My late husband was an active member of the Haemophilia Society for as long as he was able but suffering from Hepatitis C for more than 30 years had taken its toll and laterally, he was unable to participate in their activities. After his death in 2015, I went along to a meeting of the SIBF as I wanted to become involved in the campaign for the rights of those infected and affected by contaminated blood. I was appointed Treasurer after a few years and more recently took the position of Convener around two years ago, taking over from my predecessor and friend, John Rice. As Convenor of the SIBF my role involves providing leadership functions in accordance with established standards, in particular the Charities and Trustee Investment (Scotland) Act 2005, and amendments to the 2005 Act from Part 9 of the Public Services Reform (Scotland) Act 2010, chairing meetings of the Management Committee, members meetings and sub-groups as required, preparing agendas for meetings, representing the organisation externally, for example to Government, the media and funders, ensuring timely compliance by those in the roles of Vice-Convener, Treasurer, and Secretary in meeting their responsibilities, supervising and liaising with any employee, contractor or other service provider to the organisation and acting as signatory to the organisation's documents, contracts, communications and reports.

5. My name is Thomas Leggate, my date of birth is GRO-C 1970, and my address is known to the Inquiry. At the moment, and for some time past, I contribute to the work of the SIBF through an unpaid voluntary role, which I carry out in my free time outwith work. I am neither infected nor otherwise directly affected by receiving contaminated blood or blood products. I am a fully qualified chartered certified accountant with many years of experience within the charity sector. I was made aware of an opportunity to provide part-time management and project delivery services on a self-employed contractual basis by a member of the SIBF. I was already working as a self-employed contractor, so the opportunity fitted well for me. I have an interest in supporting community-led groups to maximise their impact through better use of available resources. With a strong sense of opposing injustices, the focus of activity by

the SIBF allowed me to use my experience of managing and leading projects at the coalface to help this notable and determined group of people to achieve their aims. While having to earn a living like everyone else, I nevertheless was generous with the costing of my services. I have maintained my involvement after financial funding for the charity was withdrawn. Unfortunately, this coincided with a ramping-up of activity to advocate for and represent members. This has caused severe capacity issues, but I remain a strident advocate on behalf of the organisation, many of whom I can count as friends.

6. I am responsible for the day to day running of the Forum, liaising with Trustees and Committee members, organising and running the weekly member Zoom meetings, updating the SIBF's website, organising trustee as well as general meetings, answering member's queries, liaising with Scottish Government officials, representing the SIBF at the SIBSS (Scottish Infected Blood Support Scheme) Advisory Group meetings, preparing the SIBF annual accounts and OSCR submissions and advocating for members on Infected Blood Inquiry relevant matters.

Section 2: Charity and Role

Describe the role of the SIBF, including in

a. *Providing support and assistance to members of the bleeding disorder and transfusion community*

7. The SIBF offers information, advice, and advocacy to all people in Scotland who have been affected by contaminated blood. This includes those with specific conditions such as haemophilia and those infected via blood transfusions who have all been exposed to infections such as viral hepatitis, HIV and vCJD where such infection has been as a result of medical treatment, as well as the families or carers of such persons. Since its inception in 2012, the SIBF has provided an invaluable service to all those in the infected and affected community. Membership has grown to around 180 people infected and affected in Scotland. Membership has been extended to those infected

outside of Scotland to allow them entry to our peer-to-peer support network and weekly forum meetings. There is an equitable split of members affected by transfusion-route and bleeding disorder-route infections. The SIBF strives for the equality of representation for all sections within the infected blood sphere and aims to provide a variety of support for all its members, including social and peer-to-peer engagement.

8. The SIBF seeks to understand the issues and needs of the people infected and affected by contaminated blood in Scotland and then to act on them. We as a charity provide information on contaminated blood issues in a variety of formats to all our members and those that follow our work. These have included regular newsletters, mailshots, hard copy publications and regular online updates on the SIBF website, as well as informative presentations on issues we feel are important to our members.

9. The SIBF works hard to facilitate face-to-face meetings with our members whenever we can, in person, online and sometimes a combination of both to keep engaged with our community. We pride ourselves on the high degree of regular member contact we facilitate, despite capacity and funding issues.

10. We provide informed support for all who feel they need advice, whether it concerns their physical or mental wellbeing. We take the time to respond as a charity to any and all enquiries that reach us. Often our members are seeking answers, and these can be day-to-day enquiries or larger questions about their place in the world of contaminated blood. We do what we can to provide those answers to our members, as well as anyone who contacts the SIBF. We hope to and work towards providing the kind of clarity and support that the infected, affected and wider community in Scotland were denied on contaminated blood issues for so many years. We are proud to have an engaged membership and a democratically elected Executive from the infected and affected community, with a wide range of expertise, that enables us to address a broad range of issues for those we serve. While our Trustee committee provides the governance function of the SIBF, the organisation is very much member-led,

with members having invaluable experience, knowledge and skills they can bring to bear on all of our work.

11. The infected and affected people of Scotland, as well as the rest of the UK, have faced the historic problem of insufficient specific support for those suffering as a result of contaminated blood. The SIBF offers a range of non-professional support options and avenues to those with particular vulnerabilities resulting from viral infections. We also offer more intensive and direct professional specialist support for our members to assist with areas such as state welfare benefit claims and appeals, where funding or volunteering capacity allows. We act to guide our members to other services that are most relevant to their needs when their enquiry is not something we can specifically address. This could be for example, directing them to SIBSS for state-provided financial support matters or to the Scottish Infected Blood Psychology Service for mental health support.

12. The SIBF represents the views of members and the wider contaminated blood community in Scotland when engaging with the Government, statutory bodies and other advisory or working groups. The SIBF has been honoured to play a role in representing those we work for at numerous Scottish Government consultations, Public Inquiries and investigations, and other stakeholder engagement opportunities for the infected and affected and have done so since our organisation's inception. This engagement with state and third sector bodies has also afforded us the opportunity to collaborate with a number of other charities in the contaminated blood sphere, such as Haemophilia Scotland, allowing us to work cooperatively and collaboratively to further shared goals for our communities.

13. We also play a role in supporting our members at this, the Infected Blood Inquiry. The SIBF's role and relationship with the Inquiry is discussed in more detail below, however for the members of our organisation that wish to engage with the Inquiry, we have supported and continue to support people in giving both written witness statement and oral statements to the Inquiry, supporting these individuals in the gathering of documentary evidence, including assisting

them to cope with the impacts of re-living their experiences. We take the time to explain and contextualise what happened to them and their loved ones, enable them to express how they feel, to convey what they think should have happened in hindsight, and what should happen as a result of the Inquiry.

14. We also provide a forum for gathering, prioritising, and communicating the collective responses of infected and affected people to inform the activities of recognised legal representatives at the Inquiry and act as a conduit for information sharing. We achieve this through regular engagement with our members through surveys as well as online and face-to-face meetings.

b. *Campaigning or advocating with aims or activities that are relevant to the Inquiry's Terms of Reference*

15. The voices of the infected and affected have been ignored for decades and this issue has been most prevalent when it comes to forming an understanding of what problems our community are facing on a day-to-day, as well as an ongoing basis. To address these historic problems, we regularly carry out community engagement with our members and the wider community so we as an organisation have an up-to-date and true-to-life understanding of the issues facing the infected and affected people we serve.

16. The SIBF advocates for the needs of our community to Government as well as state bodies such as the National Health Service (NHS) or Department of Work and Pensions (DWP) to ensure that there are appropriate resources to meet the needs of the infected and affected. The SIBF has been a champion of expanding payments to any section of our community we feel has been left without redress or without comparable support. For example, in January 2018, we advocated strongly for the maximisation of annual payments to Stage 1 widows with the Scottish Government by writing to the Cabinet Secretary for Health and Sport, Shona Robison MSP. This letter is exhibited under **WITN7165002**. This letter conveyed our and our member's desire for an award of £30,000 to Stage 1 widows to reflect the disparity they were suffering in comparison to Stage 2 widows under the current compensation scheme. Our

campaign resulted in us obtaining a £10,000 commitment from the Scottish Government for Stage 1 widows and, subsequently, we made both verbal and written arguments for the payment to be uplifted to the £30,000 we had initially proposed, which were successful.

17. Additionally, the SIBF carried out intensive and time-pressured work in relation to changes to the SIBSS scheme arising from the work of the Clinical Review Group. Our Manager produced a financial model to show cost/benefit permutations for Scottish Government and scheme beneficiaries and discussed and shared this with Scottish Government officials with a view to modifying their initial position that was to yield, in our view, insufficient amounts for beneficiaries. This model was also produced and discussed at length with the then Cabinet Secretary for Health, Jeane Freeman MSP, to aid her and her officials in final deliberations before the SIBSS changes were announced. We view this work as an important intervention to maximise increased annual payments for SIBSS beneficiaries, within a realistic budget and to achieve the 'buy-in' from the community in Scotland, which we represented. Whilst we did not get everything we advocated for, the resulting improvements made the Scottish scheme the most generous in the UK at the time, with the Junior Scottish Minister for Health, Joe Fitzpatrick MSP, declaring it the 'gold-standard' scheme in the UK. It led the way for commensurate increases across the rest of the UK, and ultimately was significant to the parity exercise recommended by Sir Brian Langstaff and implemented by the UK schemes. Our work in this sphere has ultimately therefore had a lasting legacy for all those in the UK and is one which we are immensely gratified by.

18. As well as those left without support, we have been persistent in the pursuit of ensuring compensation (or an equivalent but differently named payment) is made to those in our community in as prompt and timely a fashion as possible; especially given the ever-increasing death rate and frailty of those infected by contaminated blood. In June of this year, the SIBF wrote a letter making a strong and direct argument to the Rt Hon Michael Ellis QC MP, HM Paymaster General, in support of interim payments for infected people being introduced

as a matter of urgency. This letter was then followed by a direct appeal to the Prime Minister, Rt Hon Boris Johnson MP in July of this year. These letters, co-signed by numerous infected blood representative groups including the Contaminated Blood Campaign, the Haemophilia Society and the Haemophilia Society Northern Ireland, The Hepatitis C Trust, The Terrence Higgins Trust, Bloodloss Families, Factor8Positive Women, Contaminated Whole Blood UK, the Manor House Group and taintedblood are exhibited under **WITN7165003** and **WITN7165004** respectively. Through our Manager, during direct consultation meetings with Sir Robert Francis in November 2021, our organisation was the first to make arguments in support of Interim payments, both justifying the compelling need for such payments, as well as quantifying a suggested appropriate level of interim award of at least £100,000. The issue of interim payments had not been on the agenda at the start of the Infected Blood Inquiry, but the SIBF's work to advocate and press for this kind of compensation is a historic achievement for our organisation and our fellow representative groups; not least because it should provide a life-changing payment that provides greater security and dignity to the majority of Core Participants. It has been another 'legacy' piece of work with expected impacts which cannot be overstated and will substantively and timeously improve the lives of those infected and affected who benefit from these payments. The fight for the others still excluded goes on.

19. Another milestone for the SIBF arising from the collaborative activity with Haemophilia Scotland was the Clinical Review Group. This came about through the activity initiated by the Scottish Government to follow-up on some of the unfinished business from the Financial Review Group's activity in the aftermath of the Penrose Inquiry in 2015. The Clinical Review Group had a focus on considering the extra-hepatic impacts on people arising from NHS-acquired viral hepatitis; given that the previous Stage 1 and Stage 2 demarcation was recognised as flawed and not fit for purpose. It led to the unique, highly innovative, progressive, and transformational self-assessment initiative. However, after accepting the proposal, the Scottish Government assumed the role of drafting guidelines for people when making the self-assessment declaration. The SIBF quickly recognised how some aspects of

these guidelines were completely inappropriate and required to be challenged. Correspondence went as far as the First Minister, and thankfully many (but not all) of the worst elements of the guidelines were changed.

20. Another component of SIBF's campaigning efforts is having a presence and relationship with Scottish and UK media outlets. This can involve providing quotes, statistical information, campaign messaging, human interest stories, and if required, putting forward spokespersons for extended interviews, as well as supporting members during their own interviews. This gives us the opportunity to present our community's take on the issues of the day, spreading awareness of the issues most important to us, and affords the wider public the chance to view the issues facing sections of their community they may not have had the chance to consider before. For example, our contributions to the campaign for the introduction of interim payments, as discussed above, was featured in a number of news and media outlets including The Sunday Times, The Guardian as well as many others. This created opportunities for various other representative groups to access further national and local media opportunities. This presence in the media also affords us the opportunity to address and respond to misinformation on contaminated blood issues that might lead to discrimination or stigma for our community. We are well placed as an organisation to represent an accurate picture of the reality facing those impacted by infected blood and blood products, and we take that opportunity whenever we can.

21. The SIBF has had a regular and vocal presence in numerous policy and decision-making settings, including steering and advisory groups hosted by both the Scottish Government and other third-party agencies that will be outlined in further detail below.

22. The SIBF was an ever-present voice in the discussions about what form the Infected Blood Inquiry, announced by the UK Government in 2017, should take. Such actions are always motivated by the desire to represent the needs of our member-community. This included the SIBF producing a joint position paper published in November 2017 titled "Joint Position Paper – UK

Contaminated Blood Inquiry", in collaboration with Haemophilia Scotland, on what we deemed essential features of the Inquiry for those we represent. This paper is exhibited under **WITN7165005**. Our work falling from this paper is discussed in more detail in section 5 below. The SIBF also participated and engaged with other stakeholders throughout the establishment of the Infected Blood Inquiry, for example, in the drafting of the Terms of Reference and meeting with the Chair, Sir Brian Langstaff, prior to the start of the evidence gathering process. As an example of our representative efforts at this Inquiry, after these initiatory activities were completed and the Inquiry's work was underway, the continued open channels with members highlighted a topic not adequately covered by the initial inputs to the consultative processes; that of the impacts on carers, particularly in relation to end-of-life situations. It was pleasing for the SIBF to see a greater focus placed on palliative care and carer issues at this Inquiry in response to our advocacy efforts, in part at least.

c. Facilitating peer support, learning and information sharing between members.

23. The meetings that we arrange and host for our members are one of the primary ways we establish a dialogue with our community and provide them with peer support, information updates, opportunities to express their views and like-minded social contact. These meetings are held regularly, with online meetings being held once a week and in-person meetings being held as often as funding, and good will, allows. Our member meetings give us an opportunity to present the latest developments in contaminated blood and the issues closest to the work of the SIBF, as well as to field any questions our members may have. While of course the presenting of these developments is a vital part of our member meetings, we strive to ensure they are not over-scheduled with formal business so that there is sufficient time and space to engage with our members more informally. Our meetings allow people to get together to share experiences, exchange information, socialise, catch-up on personal and family news, share talents and interests, unload, share their burdens with a supportive community and uplift one another.

24. Further to our desire to represent as many groups within the infected and affected community as possible, we also host joint meetings with Haemophilia Scotland, as some people are members of both organisations. Our groups meet to work collaboratively on issues that impact both our organisations; and enable us to make stronger lobbying efforts as a collective on the issues on which we and our members substantively agree. It is unfortunate that for too long it appears that division characterised the work of many groups South of the border. We in the SIBF took a conscious decision to focus on what unites us rather than what divides us. The synergies accruing from such an approach are significant.

25. Encouraging and fostering opportunities for peer support between our members brings us closer together as a community and, in our view, only ever stands to strengthen the bonds that make the SIBF a truly member-led group. Though always optional, we ask permission from our members to share their contact details with other members experiencing similar circumstances, for example, parents with other parents or widows with other widows. Empowering those with shared experiences to reach out to each other and support one another, as well as allowing members with more experience to guide, for example, newer members who may not be aware of the types of support we provide or the context of individuals facing contaminated blood issues. These considerations are key for us in that sense of togetherness we try to provide with our peer-support. The SIBF is a close-knit family, and we take the time to reach out and ensure no member is left feeling isolated or alone through regular contact with each person in our membership base. Peer support within SIBF can also take the form of creating project-based situations that allow experienced and competent members to volunteer their time and talents to supports others. This often takes an interpersonal focus, with our more senior members using the wealth and depth of their experience and knowledge to translate complex issues, such as our numerous campaigning efforts, to the rest of our membership. Some of these efforts have also included designing and delivering projects that have allowed our members to record for posterity their experiences, and share these with others in similar situations, helping to create a sense of common cause and belonging.

Please confirm when the SIBF was set up, what prompted or led to its establishment and what its aims and objectives were or are.

26. The Scottish Infected Blood Forum is a Scottish Registered Charity and was formally established on 4th October 2012 under Scottish Charity law with the regulating body, OSCR. The establishment of the charity was an initiative led by Philip Dolan, in association with Thompsons Solicitors and assisted by GRO-A GRO-A. The SIBF charity operates as an unincorporated association with the main purpose of the organisation being "the advancement of education, the promotion of equality and diversity, the relief of those in need by reason of age, ill health, disability, financial hardship or other disadvantage" (adopting the language of the Charities and Trustee Investment (Scotland) Act 2005)

27. In the lead up to the Penrose Inquiry, Philip Dolan, along with representatives of Thompsons Solicitors recognised there was no forum for all of the infected and affected people in Scotland to come together as a single body. Specifically, while there were recognised groups which represented people with bleeding disorders, there was no entity which could assemble and engage those who had become infected by receiving whole blood transfusions (the majority of infectees) or other procedures not associated with having a condition such as haemophilia. Accordingly in 2008, Philip Dolan, set up the Scottish Haemophilia Forum (SHF) to bring together and offer support to all victims of the contaminated blood scandal. The SHF was an unincorporated association of volunteers. In 2012 the management committee of the SHF took the decision to put the organisation and the work it did on to a more formal footing as a charity and founded the SIBF.

28. Thompsons Solicitors had been acting to support anyone in Scotland who was a victim of the NHS Contaminated Blood Scandal. Initially, this was led by the legal campaigner, Frank Maguire. But after his untimely death that role was taken up by, Patrick McGuire, who continued the campaigning work that sets

Thompsons Solicitors apart from other law firms. Thompsons' access to clients or potential clients from the haemophilia community was much more readily available through their pre-existing and developing bleeding disorder support groups. However, transfusion patients were only becoming known as they responded to news items (for example, after seeing Philip Dolan speak to the media), or seeing posters on noticeboards, having a conscientious medical professional flag-up an opportunity for support or receiving referrals from the Scottish Law Society. Whole-blood infectees often became involved as individuals or lone families, and until making contact, they often thought they were the only people who were in their situation in the country. We are welcoming newly found transfusion cases still to this day.

29. As registered, and adopting the language of the Act, the SIBF's charitable objectives are the advancement of health and education, the promotion of equality and diversity and the relief of those in need by reason of age, ill-health, disability, financial hardship or another disadvantage. In furtherance of these objectives the charity provides a forum for persons affected by the administration of infected blood products or tissues:

(i) To meet in the context of a forum having a common interest,
(ii) To exchange information between individuals and bodies,
(iii) To provide mutual support, advice, and guidance,
(iv) To inform the wider society of the relevant issues, and
(v) To advocate for the needs of such people.

30. The SIBF is the only recognised charity in Scotland that seeks to provide support to all individuals (transfusion and bleeding disorder related) who were infected with viral hepatitis and other pathogens and / or blood borne viruses as a result of NHS treatment with blood or blood products, in particular by including those infected or affected by whole blood.

Describe the main activities of the charity, and any outcomes achieved by the charity over the years since its establishment.

31. The main activities of the SIBF are discussed in detail in the sections above however there have been a number of key outcomes achieved by our organisation that have formed the foundations of our ongoing work and effectiveness as a representative body.

32. Firstly, our persistent campaigning and advocacy on the issue of compensation and financial redress for our community. These efforts have included:

    (i) Assisting numerous individuals and families to access more commensurate support payments from SIBSS,
    (ii) Achieving a back-payment from the Department for Work and Pensions totalling £1.2million for over 80 people with bleeding disorders who were inadequately assessed for Personal Independence Payments,
    (iii) Assisting numerous individuals to successfully progress through DWP Benefit Mandatory Reconsideration and Appeals processes, including to the Upper Tribunal,
    (iv) Playing a key part in convincing the Scottish Government to significantly uplift payments through the Scottish Infected Blood Support Scheme, to include a less derisory lump-sum to widows, and to allow for self-assessment of the impacts of viral infections,
    (v) As well as our role in the collective efforts to secure greater parity across the four UK schemes following the intervention of the Chair of the Infected Blood Inquiry.

33. Secondly, we would like to note our successes as a representative organisation for our members, particularly in:

(i) Providing on-going intensive liaison with Thompsons Solicitors, the Recognised Legal Representatives during the Penrose Inquiry, in the face of minimal resources and an unaccommodating Chair,
(ii) Securing project funding to gather testimonies and stories of members relating to their experiences of living with the effects of contaminated

blood, and record peoples' experiences of engaging with a Public Inquiry following the conclusion of the Penrose Inquiry,

(iii) Influencing the policy and materials to be used by Social Security Scotland as it takes over and creates specific welfare benefits, for example, in relation to rare conditions, bereavement support, application and assessment protocols, as well as their appeals processes,

(iv) Drafting input for, and liaising with, medical professionals in the drafting of guidance for various state bodies on the health conditions of our membership.

34. Thirdly, we are perhaps most gratified by the platform and social group we have created for our members. We have created an environment where our members feel safe, supported, empowered, and emboldened to thrive as members of the infected and affected community in Scotland.

If applicable, describe how the SIBF's role in supporting those affected by infected blood has changed over time.

35. The SIBF has had to be a dynamic, flexible and responsive organisation as its external environment has undergone changes, often as a result of our campaigning and advocacy work. Originally, given our organisation's creation in 2012, the focus of the SIBF was on the Penrose Inquiry. During this time, our organisation acted primarily as a two-way conduit to represent members' views and their needs to Thompsons Solicitors, the recognised legal representatives at the Inquiry. We aimed to create an informed and safe setting for infected and affected people to coalesce around the issues at the Inquiry and provided information and practical support to further people's understanding of the Inquiry to assist them in engaging with it.

36. After the shocking disappointment of the Penrose whitewash, the activity shifted to making the best of the opening door provided by the Scottish Government who might not have wanted to admit it but seemed to be embarrassed by the paucity and pomposity of the Penrose output. So, following the conclusion of the Penrose Inquiry, the SIBF's role changed. This

time the focus was on making the best of the engagement opportunities provided by the Scottish Government in the aftermath of the Inquiry; created, in our view, in acknowledgement of the Penrose Inquiry's limited and disappointing conclusions. A major development and change for our organisation during this period arose from the commitment by the Scottish Government to a three-year core funding programme to both the SIBF and Haemophilia Scotland. The SIBF also sought and obtained some small project grant funding to assist us with these engagement opportunities. While there was notable disparity between the core funding awarded to our respective organisations, these funding sources enabled us to engage with our members and the wider community in Scotland through the opportunities created by the Scottish Government to further a collective understanding of and responses to the contaminated blood issues in the years that followed.

37. The announcement of the UK Infected Blood Inquiry resulted in yet another shift for the organisation. With the SIBF having more members than ever and being presented with a new opportunity to directly engage with contaminated blood issues, the SIBF's Management Committee was strengthened with further members and expertise to enable the organisation to meet its goals at this, the Infected Blood Inquiry. Unfortunately, around this time towards the end of 2018 and beginning of 2019, as the SIBF was preparing for the Inquiry, the Scottish Government withdrew its core funding for our organisation. This placed a great strain on us and our staff, who were already making the best of a small budget to serve our membership. However, this Inquiry was seen as the last chance for the infected and affected people of the UK to achieve a just and fair outcome, so despite funding concerns, we dug deeper. This resolve was particularly important when the Inquiry began gathering witness statements from the infected and affected. The emotional and physical pressure on those providing witness statements was immense, and our members needed our support like never before.

38. The outbreak of coronavirus (SARS-Cov-19) marked another period of intense change for the SIBF where we adapted to meet the new needs of our members during the global pandemic. Many of our members, who rely on the

social network and environment of support we provide, were at risk of becoming chronically isolated as a result of the lockdown restrictions that kept many indoors and alone for unprecedented lengths of time. In response to this risk, we made efforts to shift our regular member meetings online, with meetings being held on Zoom once a week (a practice we have continued unfunded to this day). These meetings proved to be lifelines for many of our members, and allowed to us to continue to support them, even from afar. The value of these meetings cannot be overstated. We received many statements from our members during this time expressing their pleasure and gratitude for the continuation of our meetings, even in a new format. The SIBF has received accolades and acknowledgement from the Scottish Government's Scottish Infected Blood Psychology Service (SIBPS) for "providing a phenomenal service to people who are in great need of support". Regular online meetings also proved vital for enabling us to engage and understand the views of our members in relation to issues being considered at the Infected Blood Inquiry.

39. The continued coronavirus restrictions during this period, resulted in a high workload being placed on the members that volunteered their time for the organisation and on our Manager (who was working pro bono) to support our members as the Inquiry considered some of its most technical and political topics. However, with the Inquiry drawing to a close, and with such a long period of valuable engagement with our membership, we have a clear picture of our core activities for the future. These include: maintaining our peer support facilitation, assisting people in coming to terms with the outcomes of the Inquiry, providing assistance with accessing the financial and other outcomes of the Inquiry (whatever they may be), continuing to provide and exchange information with our membership, and ensuring we play a direct role in supporting and monitoring the delivery aspects of post-Inquiry activities.

40. There are also a number of project actions which have been tabled by the SIBF that have been on hold until it's role at the Inquiry has been completed and financial resources are again available, hopefully. These future projects include; an oral history project, participating in plans for progressing a contaminated blood memorial, maintaining close links and liaising further with

the Scottish Infected Blood Psychology Service, a self-management seminar programme, capturing and reporting the learning and insights from our work at The Infected Blood Inquiry, a bespoke healthy living project, a creative arts response for those caught up in the worst treatment disaster in the history of the NHS, furthering our network of infected and affected friends, supporting other infected and affected communities in jurisdictions where justice has still to be progressed (such as Australia), participating in the efforts to establish a "Hillsborough Law" and related initiatives to enhance access to justice for disempowered people.

Section 3: Involvement in committees and/or working groups

Set out the SIBF's membership, past or present, of any committees or working groups the charity has been involved in, with relevance to the Inquiry's Terms of Reference. Please provide dates where applicable and set out the leadership structures of the working groups.

41. The SIBF has been involved in a number of committees and working groups relevant to the Inquiry's Terms of Reference including:

    (i) The Contaminated Blood Financial Review Group, Chaired by Ian Welsh between 2015 and 2017,
    (ii) The Scottish Government's Short Life Working Group on Clinical Review of the Impacts of hepatitis C, Chaired by Professor David Goldberg between 2017 and 2018,
    (iii) Department of Work and Pensions Working Group on Haemophilia and Contaminated Blood, Chaired by James Wolfe,
    (iv) Both the Scottish and UK PIP (Personal Independent Payment) Forums,
    (v) The Social Security Scotland Experience Panel,
    (vi) The Managed Clinical Network for Bleeding Disorders (Scottish Inherited Bleeding Disorders Network).

Describe what you can recall about any matters relevant to the Inquiry's Terms of Reference that were considered by the committee or working group of which you were a member/part of, including your recollection of the information considered by the committee or working group, the discussions held, and the decisions reached.

42. The SIBF participated in the Financial Review Group, Chaired by Ian Welsh, in 2015. The outcome of the work of the group was the publication of "Contaminated Blood: Financial Support: Conclusions and Recommendations – Financial Review Group Final Report" published in December 2015 which was put to Shona Robison MSP, Cabinet Secretary for Health, Wellbeing, and Sport. This report is exhibited under **WITN7165006.** The information considered by the Group was collected by running a consultation exercise with both SIBF and the other stakeholder communities through a series of regional meetings, surveys, face-to-face meetings and telephone calls. The Group initially created a survey that was shared with our communities to gauge their views on specific compensation issues. Five regional meetings were held to allow people to discuss their views in person and come together to consider the questions proposed as part of the consultation in a more informal way. Those who did not want to engage through the survey or via the meetings were offered the option of having private, face-to-face meetings or telephone conversations.

43. One of the SIBF's most noteworthy contributions to this report was our Note of Dissent to the final report, found at Annex D of **exhibit WITN7165006** page 44 and our Commentary on the Draft Report exhibited at **WITN7165007**. Though we wished neither of these additions had been necessary, there were many elements of this review and its report that we as an organisation did not agree with. We felt these divergences of opinion had to be formally included as a necessary caveat to the report itself from our perspective. For example, our view was that the opinions and suggestions of attendees at meetings of the group appeared to be being recorded but many of these views were not reflected in the written material coming out of the process. Further to this, we

had argued for the proposed recommendations of the report to be tested through a limited series of case studies; so that the effectiveness of the proposed recommendations could be measured against people's actual lived experiences. This suggestion was however dismissed, as were others, due to a perceived lack of time and resources. When the community was presented with a draft version of the Group's final report, we expressed our displeasure with its inadequate content and the fact that what was included disregarded a great deal of the input expressed by stakeholders at consultative meetings. In response to these complaints, we were told that the report was essentially ready to be signed off, and only minor adjustments could be made.

44. The SIBF then prepared its commentary on the draft report to try to convince those pushing the process forward of the need to stop and consider the long list of problems with the process and the report itself. However, this commentary was not welcomed, and its suggestions were largely ignored. Finally, for the sake of the integrity of the Management Committee, who were duty-bound by virtue of the SIBF's democratic process to act in the best interests of its members, the SIBF produced our Note of Dissent to the Final Report. The SIBF and other key representative groups had certainly expected to have more direct involvement in the content of the final report. We felt that the final report did not reflect a great many of the views expressed by the SIBF membership for inclusion in the recommendations and as such, we could not support or endorse the findings of the report in full.

45. The SIBF's work with the Scottish Government's Short Life Working Group on Clinical Review of the Impacts of hepatitis C, Chaired by Professor David Goldberg, culminated in the publishing of the report "Clinical Review of the Impacts of Hepatitis C: Short Life Working Group Report for the Scottish Government - Informing Decision Making on Awards for People, without Advanced Hepatitis C (HCV) Disease, who were Infected with Hepatitis C through NHS Blood Transfusion/Treatment with Blood Products, and for their Widows, Widowers, Civil Partners or Long-term Partners" in May 2018. This report is exhibited under **WITN7165008**. The SIBF's work with the Group did not get off to a good start. Based on recent experience, the SIBF had drafted

and submitted a Terms of Reference for the Clinical Review to consider adopting. The proposed Terms of Reference were designed to help avoid previous problems by bringing greater clarity and specificity to the task of the Group so there would be less room for variety of interpretation of the work to be carried out. It was understood that these Terms of Reference were acceptable to key partners, but at the point of them being considered and supported, the SIBF representative was unexpectedly and shamefully isolated. The Scottish Government officials refused to consider the proposed Terms of Reference but issued their own minimalist version and insisted that these be used. Fortunately, due to skilled Chairing, many of the anticipated issues to be assuaged by more detailed Terms of Reference were managed sufficiently; but not all. This was despite, not because of, the minimalised Terms of Reference.

46. In compiling the information and data for the Clinical Review final report, Professor Goldberg met separately with patient representatives during July and September 2017. The Group conducted in-depth analyses of Scottish healthcare data and carried out a literature review, as well as meeting to review the evidence base that had been compiled and form jointly approved recommendations, ahead of the final report being approved and later submitted to the Scottish Government. We would like to note that Professor Goldberg's engagement with the patient community as part of this report was actually inspired by work conducted by our Manager. Our Manager had conducted a series of discursive, semi-structured video interviews involving SIBF members to generate a comprehensive platform and archive of lived experience to allow people to discuss their experiences with infection and treatment, prior to the work for the report commencing. Some of these people captured on video are sadly no longer with us. The videos were offered, subject to editing inputs, and a small request for funding to do so, to Professor Goldberg for evidence of lived experience, direct from their own mouths (albeit on video) rather than in writing or audio alone. Professor Goldberg took the suggestion to Scottish Government, but officials did not recommend using the video evidence, citing the possibility of reporting bias. Professor Goldberg then carried out his own randomised interview process with SIBSS members. In actuality, there was no reporting bias, just a repetition of a process.

47. This Clinical Review Group's work resulted in the identification of a number of issues, addressed in the key recommendations of the report, that had the potential to detrimentally impact those living with hepatitis C and their families without proper acknowledgement and action. The most significant of these to us were the exploration of the factors relevant to individual assessment. We felt that the decision to require infected people to quantify and self-declare the severity of their condition from an awards perspective, without the specific intervention of a clinician or consultant, was unprecedented and extremely welcomed. However, for the SIBF, the suggestion by Scottish Government officials of leaving those in these most vulnerable positions unsupported, to attempt to quantify their suffering, alone and without support, was unfair and could easily result in a highly stressful process for the individual. Too many people had lived for so long with these impacts that they had normalised them, and so for years and sometimes decades, had under-estimated these impacts because they could not remember what it was like when they were not there. We also believed the acknowledgement of the impact of the mental health of the individual when quantifying the severity of their condition for an award was vital. Previous assessments of the impact of hepatitis C rarely took any significant note of the mental health impacts of the infection. These impacts stemming not only from the infection itself, but from its historic treatment with extremely toxic and invasive therapies such as Ribavirin and Interferon, which could leave an individual with serious and lasting issues of depression and anxiety; the severity and impact of which would be impossible to quantify without clinical assessment.

48. The DWP Working Group on Haemophilia and Contaminated Blood was established after representations were made by the All-Party Parliamentary Group on Haemophilia and Contaminated Blood (APPG). The need for this Group became evident when it was identified how so few people with bleeding disorders or those who had been infected by contaminated blood and blood products were making applications for benefits which were successful. The Group was chaired by James Wolfe a Senior Official at the DWP. Meetings of the Group were held in Caxton House in London and included various

representatives of charities and support groups. Agenda items included Employment Support Allowance (ESA), Personal Independence Payments (PIP), Application processes, Assessments, Mandatory Reconsiderations, Appeals, Warning letters, Disregards, Condition Insight Reports, and more.

49. Among the achievements of this DWP Working Group was the successful lookback over all previous PIP applications from bleeding disorder claimants due to the errors in recognising haemarthropathy as a serious enough condition and so not awarding sufficient "points" to those applicants. From this activity an amount of £1.2million was issued to over 80 applicants in backdated awards. There were also successes in securing changes to the wording of warning letters. Our SIBF representative at the group was integral to these changes and was also involved in liaising with the special team set up to handle the haemarthropathy cases, resulting in people having decisions changed in their favour and having their review periods extended to a maximum of ten years. There was also the role for the SIBF representative in providing a link to haemophilia consultants who were recruited to advise on new guidance documents for frontline DWP staff for when they came into contact with a client with a bleeding disorder or who had been exposed to infected blood.

50. However, following the sudden cancellation of one of these Working Group meetings, they never restarted; despite attempts to get them going again. Our SIBF representative on the group led the efforts to reconvene the meetings by speaking with officials and providing a list of unfinished business items. A list of these items is exhibited under **WITN7165009**. However, despite various communications and the intervention of Dame Diana Johnson MP from the APPG, the meetings have still not restarted. Sadly, this has meant that infected and affected people have continued to have negative experiences with the DWP in ways that could have been resolved through the Working Group. To date, there has not been any reason given for the lack of DWP response, apart from an initial suggestion that the Group had achieved what it had been set up to do; a suggestion that we strongly disagreed with.

51. The Scottish and UK PIP Forums work to progress issues relating to the Personal Independent Payments issued by the DWP. These are payments to help individuals with extra costs of living if they have a long-term physical or mental health condition or disability and difficulty doing certain everyday tasks or mobility issues because of their condition. Both the Scottish and UK Forum's consider issues relating to these payments, with the only difference being the jurisdiction their discussions relate to. Both Forums hold meetings that are facilitated by DWP staff who variously have responsibilities for policy, development and research. The Forums are used as a means of seeking feedback from groups who are involved with different cohorts of benefits applicants; the SIBF being one such entity/group. The other attendees come from a host of different interest groups including the visually impaired, the homeless community, people with developmental disorders, those who have suffered serious injuries, charities such as Cancer Research, support bodies, and generic advice agencies such as the Citizen's Advice Bureau. The issues discussed by the Forums include accessibility of forms and contact points, complaints, new or upcoming legislation, issues with assessment providers, initiatives to improve the PIP processes, reviews and many more.

52. Our SIBF representative at the Forums has had significant involvement in progressing issues such as the needs of claimants with rare conditions, reframing the concept of welfare benefits as a social contract, efforts to ensure a delicate approach is taken during the application review processes to protect vulnerable applicants, and the use of video and recording equipment during work capacity assessments.

53. The SIBF also participate in the Scottish Government's Social Security Scotland Experience Panels. These Panels, launched in 2017, were born from the advancement of devolution powers granted to Scotland following the work of the Calman Commission. The advancement of these powers included the Scottish Government taking responsibility for a number of welfare and benefit responsibilities that had previously been administered by the DWP. In preparation for these new powers, the Scottish Government set up Experience Panels to involve people with lived and support-giving experience with the UK

benefit system. These panels led to the creation of Social Security Scotland as the delivery arm of Scotland's welfare activity. As with the PIP Forums discussed above, these Panels are discursive settings facilitated by Scottish Government researchers where issues from key stakeholders can be presented and explored. The range of matters considered by the Panels the SIBF has been a part of have included; the ethos of a benefit system, analysis of the effectiveness of the current UK benefit system, the naming and corporate design of Social Security Scotland, the design of application forms, the design of online interfaces, appeals processes, accountability issues and many others.

54. The SIBF's representative involvement at the Panels has had a particular focus on rare conditions, the advocacy support function of benefits system, funeral support processes, case studies relevant to our community's experiences, and the prevention of the use of private contractors to perform health and work capacity assessments. Our involvement has also involved various one-to-one engagements with the state to draw on our recognised expertise in certain fields of investigative interest, for example, holding meetings with the relevant Cabinet Secretary of the Scottish Government, Shirley-Ann Sommerville MSP to engage her with areas most prevalent for our organisation.

55. The SIBF further advocates for the bleeding disorder section of its community by engaging with the recently established Managed Clinical Network for Bleeding Disorders managed by NHS Scotland, including the Scottish Inherited Bleeding Disorders Network (SIBDN). The purpose of the SIBDN is to facilitate clinical and other improvements for individuals with inherited or acquired bleeding disorders. A key aim of the network is to enable timely and effective care for individuals with bleeding disorders across Scotland. This network has taken over the facilitating of meetings between Scottish Haemophilia Centre Directors and other key stakeholders who represent patients, and since its formation, the SIBF has engaged with this type of work. When the group holds meetings, the role of Chair has typically been filled by one of the Haemophilia Centre Directors. The issues the SIBF have been part

of included new treatments, accessibility issues at centres, personnel changes, access to associated services such as physiotherapy and dentistry, audits related to the status of achieving the Comprehensive Care Centre standards and home delivery issues. These settings provide further opportunities for the SIBF to share information, represent the views of members, and feedback information to them about the work of the network.

56. A notable representative and advocacy function of the SIBF at this network came about when it was discovered that the Haemophilia Centre based at the Glasgow Royal Infirmary (Ward 1) was set to be moved to make way for a discharge hub in 2018. Once this came to light, the NHS Board hastily arranged a meeting to consult with patients over the move. It soon became clear that the decision had already been made to move the Haemophilia Centre, and that the consultation was actually to discuss carrying out the move itself. Our SIBF representative who sits on the network was instrumental in confronting the assembled NHS personnel about the of lack of an engagement processes and not following their own policies of involving patients in decision making relevant to their care. Our protests at this meeting led to a belated survey going out to patients, and a full equalities assessment being carried out on the proposal. The data from these sources highlighted a shortfall in the justification for the proposal, which was insurmountable, and resulted in the planned move being entirely cancelled. This was seen as a great achievement for many in the bleeding disorder community, since the patients of the haemophilia centre felt their needs were being made to take second place to a prestige project.

Describe the aims of the working groups and set out how they achieved their objectives in conjunction with the aims of the SIBF.

57. The Financial Review Group was tasked with undertaking a review of the existing UK-wide financial support schemes for individuals infected with hepatitis C and HIV through NHS blood and blood products, in respect of individuals and families receiving payments in Scotland. This was done with a view to making the arrangements for financial support fairer, more responsive,

more proportionate to the losses suffered, while also reducing stressful parts of the financial support application process. The SIBF's objective of the advancement of health (including the prevention or relief of sickness, disease or human suffering), was considered directly by the work of the group. The final report for example, included recommendations we advocated for to cater specially for the needs of our members on the issue of those whose health was impacted by these infections, including those with co-morbidities. This included a vulnerability to cold and a need to have a balanced diet, so the payment proposals were designed to make it easier for people to live in comfort with sufficient warmth and the availability of healthy food. In furtherance of our desire to work toward the prevention or relief of poverty, the Group made recommendations for a continuation and expansion of annual support payments, a lifeline for the most financially vulnerable sections of our membership, many of whom were solely reliant on benefits as a source of income.

58. The Scottish Government's Short Life Working Group on Clinical Review of the Impacts of hepatitis C was tasked with informing decision-making around the potential award with payments to (i) individuals who have been infected with chronic hepatitis C as a result of NHS blood, tissue or blood products, but who have not progressed to advanced disease, or (ii) their widows, widowers or partners. The relationship between the Clinical Review and the charitable objectives of the SIBF were self-evident. It was an exercise and area of work that that the SIBF's membership would have expected the Management Committee and Manager to engage with, and so we did. It afforded us the opportunity to contribute to a body work that progressed so many different areas of redress for our members in furtherance to our goals as an organisation. For example, we were able to achieve a greater consideration of the needs of transfusion infected individuals and their families, the inclusion of widows as a distinct group of eligible support recipients and recognition of the wider health impacts of the condition (including mental health).

59. The DWP Working Group on Haemophilia and Contaminated Blood was established to improve the access to welfare benefits for infected people and

people with bleeding disorders by developing better application and assessment processes as they relate to the needs and circumstances of this unique community. It was clear from its inception that this activity was highly relevant to achieving the aims of the SIBF. In particular by: advancing the health and wellbeing of infected people by enabling them to have greater means to meet their needs; providing relief for this vulnerable group by reason of ill-health, disability and financial hardship by improved financial income; and, reducing poverty through greater access to benefits.

60. The Scottish and UK PIP Forums were established to allow those organisations which work with potential PIP applicants to provide a reference group resource feeding back to the DWP on what is working and what is not working in the rollout and operation of PIP. It was clear from its inception that this activity was relevant to achieving the aims of the SIBF. In particular by advancing the health and wellbeing of infected people by giving infected people a voice in the development of a benefit applicable to them; providing relief for this group by reason of ill-health, disability and financial hardship by improving their access to additional monies; and, reducing poverty in this group for the same reasons.

61. The Social Security Scotland Experience Panels were established to allow those organisations which work with benefit applicants to provide a reference group resource that would feed back into the newly created Social Security Scotland agency on what would and would not work in the rollout of benefits under the greater devolved powers. It was clear from its inception that this activity was relevant to achieving the aims of the SIBF. In particular by advancing the health and wellbeing of infected people by giving infected people a voice in the development of a benefits applicable to them; providing relief for this group by reason of ill-health, disability and financial hardship by improving their access to additional monies; and, therefore, reducing their risk of poverty.

62. The Managed Clinical Network for Bleeding Disorders was established to bring together the service planners, service providers, and service users related to the healthcare of patients with bleeding disorders. By collaborating during

exchanges of information and perspectives, the health services for patients with bleeding disorders can be optimised in terms of quality, accessibility, safety, and efficacy. It was clear from its inception that this activity was highly relevant to achieving the aims of the SIBF. In particular by advancing the health and wellbeing of infected people by contributing to the key policy and practice discussions related directly to infected people with bleeding disorders; and, providing relief for this needy group by reason of ill-health, disability and financial hardship by ensuring the healthcare they receive is as good as it possibly can be.

Section 4: Research and Investigations

Describe, and provide details of, any investigative or research work the Forum has undertaken that is relevant to the Inquiry's Terms of Reference.

63. In March 2015, The SIBF published a research report titled "Hepatitis C Virus (HCV) Contaminated Blood Scoping Exercise Final Report" and this report is exhibited under **WITN7165010**. The report was published following meetings held at the Scottish Parliament between Alex Neil MSP, our representatives and other Scottish Government Officials to discuss the various impacts of hepatitis C on the haemophilia and bleeding disorder community in Scotland, as well as other patients who had received hepatitis C via blood transfusion. This meeting identified the need for a scoping exercise to assist the Scottish Government to more clearly understand the scope and scale of the unmet needs resulting from Hepatitis C infection and to detail the support required by those impacted by the infection. This was an activity to allow the Scottish Government to gain a more data-driven and evidence-based understanding of the needs of Scottish people infected with hepatitis C as result of NHS treatment.

64. After a short liaison period to develop the proposal for the activity, it was agreed the scoping exercise would be undertaken by the SIBF. To ensure compliance with the relevant policy requirements and properly initiate effective

community engagement, letters were sent to all NHS Medical Directors, Consultant Haematologist and Hepatologists by the Cabinet Secretary asking them to inform their patients about the exercise. Following this, a Project Reference Group was established to provide the Scottish Government with regular updates on the progress of the exercise. Due to necessary preliminary actions, the exercise did not start until May of 2014, but was empowered with a wealth of input from the infected and affected community that ensured the success of the final report from that point on.

65. To ensure the transparency of the exercise, the SIBF opted for a policy of full and open disclosure. This included the choice to invite and incorporate the views of a number of key stakeholders and partners, including patient representatives, support providers, medical professionals, and Scottish Government Specialists. The SIBF Manager and GRO-A were the principal authors of the Scoping study report. One belated problem arose when there was a difference between what had been recommended by the Scoping Exercise and a subsequent decision of the Scottish Government. It was understood that the Minister had accepted the report and its recommendations, so when the anomaly in the later decision was raised, the officials then denied that the report had been so fully accepted. This was despite the report including an introduction by the Minister which was included after the report was completed.

Outline the information or material that the SIBF found through your investigative efforts and/or research.

66. Our scoping exercise revealed a number evidence-based, and data-driven conclusions about the lives of those impacted by hepatitis in Scotland:

(i) People demonstrate responses to their infection that range from anger to resignation,

(ii) HCV infection does not discriminate by age, social class, gender, or any other measure when it was transmitted to people who came in good faith simply to access their NHS,

(iii) Many people are hugely dissatisfied by the course of events over at least the last three decades. They have lost trust (perhaps irreconcilably) in both the medical profession and in governments who some perceive wanted to hide from the truth,

(iv) Given that their infection came about through no fault of their own there is despair at the delays, misinformation, loss of documents and the apparent strain that existed between safety and savings considerations, receiving a diagnosis (if patients were ever formally spoken to at all) was not generally a good experience. There were issues of feeling like guinea pigs, being kept in the dark, not being apprised of the real risks and then having to continue to engage with the very clinicians who brought about their infection with a life-limiting condition (however well-meaning their intentions were at the time),

(v) These perceived injustices have created a group of people who have become mobilised and determined to see some kind of just outcome,

(vi) Infected people's lives, and those of families, carers and in particular the bereaved, have been significantly impacted on, not just in terms of their health and wellbeing. For some, their lives have been "turned upside down" from being regular, happy and fulfilling, into circumstances of fear, uncertainty for the future, with greatly reduced quality of life, and a range of diverse health detriments,

(vii) A significant number of people have died which, while it might conclusively resolve the problem for the "infected" person, does not relieve the pain felt by the "affected" who remain,

(viii) Beyond immediate clinical interventions to address presenting medical issues, support for needs such as helping with strained relationships, understanding and accessing benefits, addressing mental health concerns, facing threats to employment, etc. have been largely unmet,

(ix) On the matter of financial recompense, HCV infection presents as a "double jeopardy". Living costs go up at the very time when people's capacity to be economically self-sustaining go down,

(x) However, many infected/affected people seem to want to avoid the appearance that they might be involved in campaigning just because there is the possibility of compensation in the future, or "ex-gratia" payments (however derisory these may be). Yet others have unashamedly called for fair and realistic compensation for what they claim to be genuine losses including their jobs, businesses, homes and savings,

(xi) People know that they have been financially disadvantaged, and not by their own actions but by the state through one of its key public services,

(xii) Affected people know that while money does not bring back full health (and certainly not a deceased relative), lack of money is a major issue for many HCV infected/affected people, in the most practical terms,

(xiii) There seems to be great variability in people's opportunities to self-manage their condition. Services tend to be concentrated on the centres of population for logistical reasons, but this excludes many others who are scattered across Scotland,

(xiv) There is a great deal of misunderstanding among the general public about HCV and this has resulted in distinct issues, including feeling stigmatised,

(xv) Agencies that are meant to support people with needs are not always able to do so for people like those living with HCV due to its different manifestations and variability in health detriments,

(xvi) The picture in Scotland for those whose HCV infection arose from contaminated blood is one of distrust, disempowerment, emotional turmoil, personal and family tragedy, significant chronic health impairment and serious economic disadvantage. The sense is that for over 30 years the consequences have only been felt in one direction.

Describe the efforts that were involved in obtaining the information or material referred to in question above.

67. The main way data was gathered to inform the exercise was through a comprehensive questionnaire. A questionnaire was chosen to reflect the

SIBF's understanding of the sensitivities facing their community; an empathetic and measured approach for information gathering was chosen in acknowledgement that some people would be anxious or unsure about participating while others were known to hold strong views and grievances about their experiences. Our detailed questionnaire was the best way to gather accurate and representative information from both sections of the community, without prejudice to the other.

68. Our questionnaire had over 120 respondents, which was not only beyond our minimum quota for the exercise, but also well above our preferred target for community engagement.

State whether there is information or material that the SIBF was unable to obtain access to during the investigative or research work and if so, provide an outline of what the SIBF were seeking but were unable to obtain.

69. The majority of the data collected as part of this exercise came directly from our community through the engagement approaches described above and so none of this was subject to any restriction; and there was no further information or material that the SIBF was unable to access when conducting their work on the project.

Section 5: Impact

Describe how the Forum interacts with victims of infected blood and raises awareness.

70. The many ways in which the SIBF interacts with its members and raises awareness of contaminated blood issues is described in more detail in section 2 above. However, the SIBF interacts with its members through regular meetings, both online and in person, open to the infected and affected in Scotland and beyond, regular online and hard copy updates through posts on our website, emails and mailshots to our members, newsletters, and other physical publications, as well as informative presentations. To raise awareness

of the issues closest to the SIBF and its community, we have, and continue to, represent their views at Government, state body and third-party engagement opportunities, to Inquiries, as well as presenting the views and needs of our members through interactions with the media.

Outline how the SIBF supports those infected and affected in relation to information exchange between individuals and bodies or organisations.

71. As outlined above, we facilitate the exchange of information with the infected and affected community through regular meetings and a range of online and physical publications. This includes our efforts to outline and translate larger contaminated blood issues and news stories into more digestible blocks for our members, as well all those that find us. For example, since the inception of the Infected Blood Inquiry in 2018, we have posted updates on the key evidence and notable outcomes of the Inquiry on the news section of our website. These information exchange efforts also include the SIBF communicating to its members and the wider community, about the work undertaken by the SIBF on behalf of its members at the key stakeholder and engagement opportunities we participate in, such the Hepatitis C scoping exercise discussed in section 4. More recently, as the Inquiry evidence has become more technical, one of our members has been encouraged to create a blog which summarises Inquiry evidence sessions and includes a personal commentary. While the SIBF cannot be held responsible for any views expressed by the blogger, it has opened up a new means of helping people to engage with the Inquiry process, especially as some have become unable to give as much time or attention to the proceedings due to being affected by “inquiry fatigue”.

Describe the advisory, advocacy and educational and relief roles enacted by the SIBF.

72. Some of the areas outlined in this question are covered in more detail in sections 2, 3 and 4 above. However, there are further advisory and advocacy

efforts we as an organisation have participated in that we wish to note here and some we would like to expand on.

73. In section 2 we discussed how the SIBF has advocated for the needs of our community in dealings with the NHS. This has included discussions with NHS representatives on the need for, and ensuring access to, specific psychosocial support for the infected and affected (including from transfusion routes); as well as stressing the need for systems of ongoing monitoring and support for those who have shown to have achieved a sustained viral response from their infections following treatment.

74. Also discussed in section 2 above, in November 2017, the SIBF in collaboration with Haemophilia Scotland, prepared a report (Joint Position Paper – UK Contaminated Blood Inquiry exhibited under **WITN7165005**) outlining what the essential features of the Infected Blood Inquiry should be to best represent the needs and desires of our combined communities following years of neglect from the state, as well as the multiple failures of previous Inquiries such as the Penrose Inquiry.

75. In acting as advocates of the infected and affected individuals we represent, we stressed the importance of a Scottish focus for the Infected Blood Inquiry, namely there being Scottish Core Participants, with their own Scottish Legal Representation and a Scottish Legal System. The way the contaminated blood disaster unfolded across the UK, across the varying healthcare structures and Governments, was an important distinction for us on how the disaster unfolded and impacted our community. This difference of experience was something rarely acknowledged with any substance at previous Inquiries such as the Penrose Inquiry. We believed it was of vital importance that the infected and affected in Scotland had the opportunity to not only participate in the Inquiry as victims of that specific geographic experience, but to represent their experiences from the Scottish perspective in a meaningful way. To allow them to do this effectively, we made the case for these Scottish Core Participants to have Scottish legal representation to reflect what we believed to be the respective differences in policy framework, health services and legal systems

in Scotland; and ensure these differences were catered for and understood by those who would represent us at the Inquiry.

76. In addition, we also stressed the need for recognition of the stress placed on the individuals participating in the Inquiry in retelling their story and revisiting their experiences. We felt it was necessary that there was acknowledgement not only of the emotional impact of infection, but of the necessary adaptations the Inquiry would have to make to its operation to allow infected individuals to play their part in the Inquiry's work effectively and comfortably. The adaptations we advocated for included having appropriate emotional and mental health support available from the Inquiry, to stem the risks that could follow individuals exploring their past traumas; as well as adaptations to address the physical limitations of some individuals who had been impacted by the viruses considered by the Inquiry, including allowing for regular breaks in the Inquiry hearings and scheduling sufficient time for people to rest and recover between sections of evidence. The unexpected and unprecedented Covid-19 situation made these issues all the more relevant.

77. As recorded elsewhere in this statement, the SIBF was significantly involved in meetings to establish the Infected Blood Inquiry; including in the setting of Terms of Reference, the ways the Inquiry should engage with people, and on an ongoing basis, through participation in Inquiry Update Meetings. These have often been very useful, fruitful and effective ways of allowing our members to have a sense of influence on the biggest process that could bring answers and justice related to the whole Contaminated Blood Scandal. One aspect not so far covered has been the engagement with the Cabinet Office. One of the SIBF members had represented the organisation in the early stages of linking to the Cabinet Office as the Infected Blood Inquiry was just being introduced. There were a series of meetings with the then Sponsoring Minister, Damien Green. During at least one of those meetings the issue of the appointment of the Chair was raised by several attendees. Given the very negative experiences with Lord Penrose, there was a desire for the anticipated appointee to the Inquiry Chair role to be referred to the charities and informal support groups in case a difficulty or potential conflict was known within the

community which would not necessarily be known to Ministers or officials. This commitment to take soundings was duly made. However, there was subsequently a change of Minister when David Lidington was appointed. The next thing people knew was when the announcement of Sir Brian Langstaff was made, without any reference to those to whom the commitment had been made. A Freedom of Information request was submitted seeking the minutes of the meetings. It was noted that when Mr Green had introduced everyone, there was someone there from his office to take the minutes. The normal deadline for responding to a FOI request was missed, as it was for a follow-up submission. A member of the SIBF approached Mr Lidington in person at the Inquiry Commemoration event and raised the matter. He said he would follow it up and passed over a card to his Private Secretary. When again nothing was forthcoming another request was made and again the deadline for responding was missed. Eventually a request did receive a response which said there was no record of the commitment being made and no minutes had been taken. This incident was seen as foreboding since on this very early occasion the Government had failed to meet a reasonable and legal request, rather it had denied all knowledge of the matter in just the same way campaigners had been denied paperwork, information, truth, and justice. Even after seeking for the matter to be reviewed, there was no change. No documents were ever forthcoming, and it was as if the meetings with Mr Green were considered too revealing if the paperwork had been made available, or it was simply lip-service, and no actual regard was given to the people who had made themselves available in good faith to support the process.

78. There have been other engagements with the Cabinet Office, including one particular meeting in January 2020 involving Oliver Dowden MP who was at the time the Sponsoring Minister for the Inquiry; having replaced Mr Lidington. Nadine Dorries MP was the Minister from the Department of Health and Social Care with responsibility for the matters concerned, so she was also in attendance. The main reason for calling the meeting appears to have been a second attempt at providing a face-to-face response to the charities, campaigners, support groups and other core participants who were seeking to know why the call by the Inquiry Chair for a financial uplift had not progressed

in any meaningful way. Unfortunately, the meeting was not well chaired and left attendees feeling very frustrated since all it achieved was to give people unequal time slots to raise issues that went over old ground. In anticipation of the potential lack of progress at the meeting based on the material produced as part of inviting people to attend, the SIBF prepared a briefing document to consolidate a list of key issues from its perspective, and pose direct questions, or calls to act, to the Ministers who were hosting. These questions invited action, none of which would have impacted on the necessarily independent work of the Inquiry. They were all reasonable requests covering matters beyond the Inquiry Terms of Reference. Those other campaigners who commented were very positive about the briefing, believing it to be a useful contribution to the debate and campaign. A copy of the briefing is exhibited under **WITN7165011**. Sadly, but also typically, this meeting became almost completely redundant soon thereafter when Mr Dowden was given a new post in Government, and soon thereafter Ms Dorries, too. There were no tangible outcomes from the meeting other than to delay important activities even more and frustrate people further.

79. In December 2021, the SIBF, in collaboration with Haemophilia Scotland, produced a report titled "Infected Blood Compensation Framework – Scottish Consultation" This report is exhibited under **WITN7165012**. The report was created for the purpose of informing the UK-wide Compensation Framework Study being undertaken by Sir Robert Francis at the request of the UK Government. Our work as part of this consultation was funded by the Scottish Government, though the conclusions of the report remained independent of their influence. The consultation and report processes were carried out and produced by our Manager. For completeness, it is worth noting that the Sir Robert Francis work on a Compensation Framework invited contributions to the Terms of Reference for his Study. Beyond a collaborative Terms of Reference submission along with Haemophilia Scotland, the SIBF also submitted a more detailed document which attempted to introduce key content in the hope that these would be included in the exercise. This included listing principles to apply, red lines, the full range of compensation headings, the full

range of people to be compensated, and issues around assessment and administration. This more detailed Terms of Reference Consultation Response is exhibited under **WITN7165013**.

80. This consultation provided us the opportunity to frame the proposals for the then still to be announced compensation framework in the context of our community; with a view to being able to make proposals for future compensation that would directly meet the needs of the infected and affected in Scotland. We took input and feedback directly from our community for this report by circulating a consultation survey, adapted in response to the focus groups held on the issue of compensation, to give us a true-to-life picture of the desires and hopes of the infected and affected in Scotland for that framework. The questionnaire was designed to be "focused" to keep the attention of the respondents engaged, whilst ensuring there was enough depth of answers to capture and distil the key elements of Sir Robert Francis' consultation questions as they pertained to those infected in Scotland. This focused consultation survey was put to the Scheme Manager of SIBSS, who agreed to distribute it to all beneficiaries registered with the Scheme. This enabled us to paint a broad picture of the needs of our respective communities in Scotland. There were 258 responses to our consultation survey in the three-week consultation period between 1st and 21st November 2021, which represented 47% of the SIBSS beneficiary numbers at that time and well above the expected return rate for a survey.

81. The key findings of our consultation with combined Scottish communities were that most people:

(i) Did not want a process of detailed personal assessments for future payment,
(ii) Wanted compensation payments to be made as quickly as possible as lump sums, administered in Scotland, funded centrally by the UK Treasury,
(iii) Supported the proposal of an interim payment as soon as possible after the publishing of Sir Robert's report in 2022,

(iv) Agreed that SIBSS, or another provider performing the same role, should continue to exist into the future and make regular monthly financial support payments,

(v) Felt that current and past support and ex-gratia payments must not be conflated with, or treated as, part of or 'payment on account' of compensation,

(vi) Wanted compensation expanded to other family members and carers

82. The SIBF was pleased to play such an active role in collecting and advocating directly for the needs of our Scottish community as part of this process; to ensure that the voices of the infected and affected in Scotland could be heard, and their input fed directly into the foundations of the new compensation framework.

83. However, when reflecting on this consultation process as a whole, some within the SIBF that felt there were elements of the consultation response that ignored certain sections of the data collected during the engagement process, in favour of making more mutually agreeable recommendations. For this reason, the SIBF encouraged people as individuals to separately respond to the consultation with the points they felt needed to be raised, and we made clear we would support them to make these representations if requested.

Set out how the Forum benefits those within the transfusion and bleeding disorder communities.

84. The SIBF is a forum where people can be honest, be themselves, share their experiences, and offload the traumas that have burdened so many for so long. We provide opportunities for people to look beyond the pain of past experiences and release further trauma within themselves to take ownership of their lives again. The SIBF is a cathartic charitable organisation at heart and has been a release for many of us. The word forum is a good representation of what SIBF is, going back to the Latin, and adapting it, our Forum is a place where anyone can come and say their piece, and receive peace, without being shut down or censored. It is a place for honest discussion, where there is a

sense of belonging, comradeship and a fight for a common cause. It's the only setting that some people have where they are comfortable enough to admit they have these infections, which are still heavily stigmatised, and discuss them without judgement. Our support has given people a sense of control over their lives again, allowing them to tell their story and explain and explore their thoughts. We feel a great sense of satisfaction and gratitude in having people allow us their time and energies so that the voices of our members can be incorporated into everything we do.

85. The work of the SIBF and the support it provides to its members is invaluable, and this work must continue beyond the conclusion of the Infected Blood Inquiry to ensure the foundations of support we have built for our community can be sustained and built upon. Clinicians at the Scottish Government's SIBPS (Scottish Infected Blood Psychology Service), for example, recognise the substantial and unique impact the charity has on the infected and affected people it can reach, even with limited and curtailed resources. It has been acknowledged by these experts in our work with them that the SIBF has been a huge help and provided a phenomenal service to infected and affected people who are in great need of support. The SIBF is the only registered charity, not only in Scotland but in the UK, that seeks to help both the transfusion community and bleeding disorder community of infected and affected people. This valuable work is simply unsustainable without funding and is in real jeopardy of ceasing at the precise time when the service provision needs to ramp-up to meet the demand of the community it serves.

Section 6: Funding

Please set out the funding framework that currently supports the Scottish Infected Blood Forum. If applicable, please explain how this has changed over time.

86. The SIBF received £25,000 of core funding from the Scottish Government in 2016 which enabled us to engage sessional project and management staff, on a limited part-time basis, until around March of 2018. A proportion of this core funding sustained our activities into 2019, but once that had been spent, we

have received no further core funding for our work as an organisation from the Scottish Government; with the Scottish Government making clear to us that they did not have a sufficient budget to continue providing core funding to us. The SIBF also received an injection of £5,000 in 2014, and £7,500 in 2015 under the Scottish Government's Section 16B Grant Funding Scheme. However, this scheme was discontinued in 2016.

87. Outwith Government funding sources, the SIBF received and an award of £10,000 in 2014 and a further £10,000 in 2016 from The Health and Social Care Alliance Scotland (the ALLIANCE), for the production of a documentary entitled "Living Well", which is exhibited under **WITN7165014**, a grant of £2,000 from Gilead Sciences in 2016 for the SIBF Scottish Parliament Event, an award of £10,000 from The Big Lottery Fund's 'Investing in Ideas' initiative in 2018, further awards of £9,975 in 2018 and £10,000 in 2021 as part of The Big Lottery Fund's 'Awards for All' initiative and an award of £5,000 in 2021 from Foundation Scotland. At present, The SIBF is now in the unfortunate position of being kept just above insolvency by member donations to our organisation. The SIBF's Summary Receipts and Payment Accounts for the years 2013-2022 are exhibited under **WITN7165015**.

If applicable, please outline how future funding is being provided to the SIBF.

88. At the time of writing, there are no live funding prospects for the SIBF. This leaves us in a position whereby there is no funding for any of the services, member support, staffing and all the other activities of the charity we aim to provide for our members.

Please set out how the SIBF sees its work developing in the future so that the support provided for victims can continue in the long-term.

89. The reality for the SIBF is that without funding, our work and ability to support our members in the future is entirely dependent on the goodwill of the Manager who for some time has worked pro-bono, as well as those who donate to us and volunteer their time to the organisation. Whilst all donations are

appreciated and very welcome, we can only speculate when looking forward to the future as to what funding we will have to operate our organisation. The charity has for some time relied heavily on the goodwill of its Manager and Trustees. We have previously listed a set of project proposals identified as wanted by our members and would hope to realise at least a few of these. We are of the firm view, and supported by expert independent clinicians at SIBPS, that even after the Inquiry ends, and even after the compensation issue is settled, there will remain a significant need for the SIBF to be funded to continue to provide the services to members which they have come to value so much.

90. It is prudently estimated that the manager post requires funding at the bare minimum of at least 3 days per week. A full-time post would offer the best service provision and provide an ‘on-call’ service to infected and affected people. A commensurate full-time equivalent post would require a minimum annual salary of approximately £40,000 p.a. The manager who currently provides services pro-bono has a wealth of unique and exclusive experience that money simply cannot buy. To allow him to take on a full-time post would allow him to realise the full ambition of the service. This however will require a higher level of secured funding with the guarantee of index linked increases to ensure the role’s longevity. The strong and supportive relationships that have been built-up over years are evidence of the unique and lasting effectiveness of the services provided. New members enter the forum and benefit from the living legacy of the Manager’s and Forum’s endeavours. Correct and appropriate funding for this continuing endeavour, and for the survival of the SIBF, is vital.

91. We are concerned about the message which the ongoing lack of Government support sends out in the face of this Inquiry, which is specifically examining the response of Government to the circumstances of infected and affected people. There is a strong case for having a sustained parallel support process to run alongside individual payments arrangements (i.e. compensation and regular financial support payments) for as long as there are infected and affected people in the community. That parallel process is for the human interaction

between infected and affected people in the form of the SIBF programme of work. This is made up of core activities (meetings, communications channels, awareness-raising, support to individuals, etc.) and the bespoke, thematic projects (as previously mentioned). These core activities match the realisation and ambition of the SIBF's potential, and they fully meet the needs of the infected and affected community. We recognise that to properly provide for these needs and offer a full service level provision, the paid human resource component would require two full-time equivalent posts, not just a Manager's post. The two salary ranges would be (a) Manager at £40,000 to £45,000 per annum, and (b) Project Officer at £25,000 to £30,000 per annum. These salary levels reflect the unique experience and knowledge required for these posts. With on-costs this would come to an initial annual salary budget of approximately £75,000 in total. Other non-capital spending (office space, utilities, phone/Internet, stationary, insurance, etc.) would amount to approximately £50,000 per annum. So, an annual budget of approximately £125,000 rising each year with inflation would likely be required into the future. This level of support to the SIBF will maintain the provision which people value so much. It would be seen as part of the non-financial support recommendations (non-financial in the sense of not being monies going directly to individuals) arising from the Inquiry investigations. The SIBF is ideally and uniquely placed to provide the services as described herein to the infected and affected community in Scotland. There is no other body with the specific role of supporting Scottish people impacted by the NHS Contaminated Blood Scandal. We have the experience, the contacts, the people, the intrinsic knowledge and the goodwill of the community to draw upon. This assertion does not diminish the role or value of our common-interest collaborators, in particular, Haemophilia Scotland whose remit includes supporting bleeding disorder people in relation to infected blood, but not transfusion victim-survivors, and certainly not exclusively State-infected bleeding disorder families.

Section 7: Other Inquiries

Describe any involvement that you have had with any other inquiry (such as Archer, Penrose or Lindsay).

92. The SIBF trace our roots to the SHF which was established as a response to the announcement of what became the Penrose Inquiry. The creation of the SHF was a means of allowing Thompsons Solicitors to engage directly with the infected and affected members of its client group, in particular, those in the transfusion cohort, who previously had no support group or representative body.

93. At the time of the announcement that there would be a Scottish Inquiry it was deemed important to have a coordinated Scottish voice through which there could be communication between the Scottish Government, the Inquiry, the recognised legal representatives and the people of Scotland who had been infected and affected by contaminated blood. The most active local group operating under the umbrella of the Haemophilia Society (as the UK-wide parent-body) was the West of Scotland group. But there were also groups in Dundee, Aberdeen, and Edinburgh. The capacity of these groups to be active in campaigning was often limited by the health, or rather the ill-health, of those who had been involved in leading them. By a long way the largest group was in the West of Scotland. The Chair of the West of Scotland Group was Philip Dolan. He had developed a close working relationship with Frank Maguire of Thompsons Solicitors. They had both been members of the Lord Ross Expert Group. So, to facilitate the easier and closer-to-hand liaison, Philip Dolan established the Scottish Haemophilia Forum (SHF) and sat as its Chair. It was not established from the outset to be a registered charity but was classed as a voluntary association. Any expenditure such as postage was funded out of the pocket of the Chair himself. Meetings were held in his home in Glasgow or wherever Mr Dolan could persuade someone to give up a space for free. It was from this basis that the targeted work to establish and link to the Scottish Inquiry began.

94. As events progressed from the announcement of the Inquiry through to the first public hearings of the Penrose Inquiry, the SHF representatives were involved continuously. Mr Dolan had become a face for the "victims" with appearances in the press and on television. As a result of this public exposure, Mr Dolan was being contacted by people who did not have a bleeding disorder, but either knew or thought they had been virally infected through receiving a blood transfusion. He became their only point of voluntary group contact. Other people were making contact with the Inquiry or Thompsons Solicitors. Eventually, it became clear that the non-bleeding disorder community needed a way to properly engage with each other, with the legal team, and with the Inquiry. This led to the establishment of the Scottish Infected Blood Forum as the only body with the specific role of representing all people in Scotland who had been infected and affected by contaminated blood. So, with the backing of Thompsons Solicitors and the SHF committee, Mr Dolan re-named the group into what became the SIBF. With the growing numbers of people involved, it soon became clear that it would be better to formalise the group, so **GRO-A** **GRO-A** was asked to use his experience in the voluntary sector to produce the necessary foundational governance documents and engage with the registration body (OSCR) which in October 2012 resulted in the formation of a new legal charitable entity, the Scottish Infected Blood Forum. That then became the body which carried on through the Inquiry process and subsequently.

95. The SHF held a number of meetings following its creation, inviting those who were interested in more actively participating in the activities surrounding the Penrose Inquiry to come along. Initially, a small number of already active SHF individuals were expected to carry out a range of representative roles at the Inquiry. These roles were overseen by the original Convener and founding member of the SIBF, the late Philip Dolan. Around this time, the work began to establish the SIBF as a recognised and registered Scottish Charity.

96. Shortly after Lady Cosgrove was initially announced as Chair of the Inquiry, the SHF began attending meetings with Civil Servants and other stakeholders to determine the Terms of Reference for the Inquiry. While the SHF and other

groups had come to these meetings with a list of issues to be investigated by the Inquiry and included in the Terms of Reference, the Civil Servants chairing the meetings discouraged the setting of a Terms of Reference document that was too detailed or specific. Their advice was that a wider scope for the Terms of Reference would mean they would be better suited to respond to new areas requiring investigation as the Inquiry progressed. We accepted this advice in good faith. Shortly after these Terms of Reference had been agreed upon and confirmed, Lord Penrose was appointed as Chair in place of Lady Cosgrove who had unexpectedly stepped down, apparently for reasons related to a potential conflict of interest due to a close connection to the medical profession. Unfortunately, Lord Penrose did not apply the Terms of Reference to cover a wider area of investigation, as we had been advised. Instead, he made it clear that if something was not specified in the Terms of Reference, he would rule it out of consideration.

97. Following the formation of the legal team, including Senior Counsel, Junior Counsel and a group at Thompsons Solicitors acting as recognised legal representatives for those at the Inquiry, 80 individuals applied to be Core Participants at the Penrose Inquiry. Regrettably, only 6 infected and affected people were granted Core Participant status by Lord Penrose and so being given the opportunity to provide oral evidence. The SHF had raised the option of judicial review in response Lord Penrose's decision to limit the number of Core Participants, but this was not pursued.

98. The SHF representatives, latterly the SIBF representatives, then began to meet with the legal team on a regular basis, and this carried on throughout the entire six years of the Inquiry. At these meetings, our organisation would provide ongoing guidance and information to the legal team, which was a huge undertaking for us at that time. These meetings were held frequently, sometimes on a weekly basis when the Inquiry was approaching a tranche of oral hearings. Our small group of representatives attended these meetings, while dealing with their own health issues, using their own resources to travel to and from meetings, search for further evidence in their own time, communicate and update other members on work at the Inquiry, participate in

further liaison meetings and attend public sessions of the Inquiry wherever possible.

99. The SIBF took great issue with the approach taken by Lord Penrose as Chair of the Inquiry towards the Infected and Affected victims of the scandal; an approach that stands in stark contrast to the compassionate approach of Sir Brian Langstaff as Chair of the Infected Blood Inquiry. For example, during his opening statement to the Inquiry, Lord Penrose stated that every penny spent on the Inquiry, was a penny taken away from NHS patient care. Further to that, when the analogy of someone having been infected with a life-changing and life-limiting virus was described by the late Philip Dolan using the familiar expression of it being like having “the Sword of Damocles” over their head, Lord Penrose interjected by saying it was more like a “feather duster”. Our representatives again raised our concerns with Lord Penrose as Chair in response to his actions, however, executive powers of the Chair under the Act meant that if a request to change a decision of the Chair was made, the consideration of that request was made by the Chair, and so the outcome was inevitable. This was one reason why there had been such a strong desire on the part of the SIBF and others to see a Chair and Panel arrangement at the Infected Blood Inquiry, rather than a lone Chair.

100. The SIBF and its antecedent organisation was actively involved all the way through the Penrose Inquiry, and frequently it was exhausting, frustrating, and ultimately unfruitful (to put it very mildly). The experience of enduring the re-traumatising, utterly disrespectful, and wholly whitewash-justified Penrose Inquiry left a deep scar on the entire organisation.

Section 8: Haemophilia Society

Describe any involvement that you have had (other than as a member) with the Haemophilia Society insofar as relevant to the Inquiry’s terms of Reference.

101. The SIBF has collaborated with the Haemophilia Society in joint campaigning efforts that further the goals of both our memberships. Our

mutual support for these common causes between our charitable organisations has been a way for both of us to strengthen our pursuit of key issues when advocating for our communities with the Government, when we have the chance to do so. For example, we liaised with the Haemophilia Society and secured their support for our letters to the Paymaster General the Rt Hon Michael Ellis QC MP, in June of this year, and to the Prime Minister, Rt Hon Boris Johnson MP, in July of this year presenting our views on the urgent need for the introduction of interim payments for the infected, as discussed above at section 2. We have similarly supported the Haemophilia Society in their efforts for the bleeding disorder community, for example, by providing our support to their activities in campaigning to the Government for greater parity, fairness and transparency for the compensation payments issues to the infected and affected across the four jurisdictions of the UK. However, our relationship with The Haemophilia Society in England has not benefited from the same depth of relationship that we have with Haemophilia Scotland, where a clear strategy of cooperation between our Scottish charities has historically yielded more numerous and consistent successes.

Section 9: Trusts and Schemes

Describe any involvement that you have had with any of the trusts and schemes established to provide financial assistance.

102. We have been involved with both the creation, and operation of, SIBSS since its inception. Our members have sat on the SIBSS Advisory Group since its establishment a few months following the commencement of the Scheme's operations in 2016. The Advisory Group is tasked with the review of operational matters for the Scheme. This covers areas such as providing advice and insight for how the Scheme interacts with its beneficiaries, working to streamline administrative issues such as waiting times for the processing of applications or responses to enquires from the public as well as the practicality of the website for applicants and beneficiaries. The information we receive to enable us to review these areas are provided to us by the Scheme Manager on a Quarterly basis.

103. This role however does not involve the examination of any strategic aspects of the Scheme's operation. This means the SIBF have no role at present in reviewing the policies or rules of the Scheme such as the level of payments awarded to beneficiaries or the criteria for awards under the Scheme. These areas remain reserved to the Scottish Government. The Scottish Government also has a seat on the Advisory Group, along with a least one Senior Civil Servant. The justification for their control over these issues at present centres around the fact that any change in the Scottish Scheme could result in the need for mirrored changes in the operation of the compensations schemes in other jurisdictions in the UK. Whilst we are of course sympathetic to these kinds of cross-border issues, we feel that the closer patient representative groups can be to these areas of strategic decision making, the more effective the Schemes will be in providing appropriate and specific compensation to infected and affected people in Scotland and the rest of the UK. Through listening to our membership, we have been notified of difficulties people have experienced with the SIBSS. We had tried to influence a customer satisfaction process, but with limited impact. The subsequent report presented a glowing picture of the organisation, without reference to any negative issues raised. There had been a commitment to a full review of the service, but this has so far not been entertained. The other financial support bodies such as Skipton and Caxton were operated under an English jurisdiction, despite them having a UK coverage, so there was no opportunity for the SIBF to influence those bodies. The hope of the SIBF is that any new "arms-length body" is at least as accountable to those who would receive payments from it as it is accountable to, and controlled at a distance by, the Government of the day.

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed **GRO-C**

Dated Sep 29, 2022