Witness Name: Patricia McGrath
Statement No.: W4098
Exhibits: None
Dated: 11 September 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF PATRICIA McGRATH

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 17 April 2020.

I, Patricia McGrath, will say as follows: -

I wish it to be noted at the outset that some infected and affected persons I have supported in my role as the Regional Haemophilia Social Worker have not engaged to my knowledge with the Infected Blood Inquiry process on any level. I have therefore tried to ensure that my responses do not identify such individuals in any way or compromise their confidentiality and I would be grateful if this could be respected.

Thank you
Patricia McGrath

Section1: Introduction

1. My name is Patricia McGrath. My date of birth is GRO-C My work address is
   Social Work Department
   N.I.C.C
   Belfast City Hospital
   Lisburn Road
   Belfast.
   My professional qualifications are as follows -

BA Hons Social Science		1990
C.C.E.T.S.W	Diploma in Social Work	1997
Q.U.B	Master of Social Work	1997
N.I.P.Q.P	Post Qualifying Award Level 1	2004

2. I have set out in the table below (in reverse chronological order) my employment history as a Social Worker prior to my appointment as Regional Haemophilia Social Worker. I have included relevant positions and dates. I have also included a brief outline of my role and responsibilities in these positions.

Name & address of Employer	**Job Title**	**Start Date**	**End Date**	**Duties**
Belfast Health & Social Care Trust, Headquarters, A Blocks, Belfast City Hospital, Lisburn Road	Social Worker	09/1/2009	31/3/2014	Providing a social work service to children with disabilities and their families in accordance with statutory and agency requirements. Liaising with MDT colleagues to assist with the assessment & intervention with service users.
Belfast Health & Social Care Trust, Headquarters, A Blocks, Belfast City Hospital, Lisburn Road	Social Worker	13/01/1999	06/01/2009	Providing a social service to the regional paediatric neurosciences MDT. Providing support to children experiencing the trauma of illness & admission to hospital. Liaising with regional community MDT's, statutory & voluntary services.
South and East Belfast Health and Social Care Trust, Trust	Social Worker	12/11/1998	07/01/1999	Providing a social work service to women & families coping with the impact and

Headquarters KBHCP, Saintfield road, Belfast				implications of a pregnancy at UHD. Supporting families of babies born with special needs facing an uncertain future. Identifying resources to support these women
North and West Belfast Health and Social Care Trust. Trust Headquarters, Glendinning house, Murray Street, Belfast	Social Worker	20/07/1998	10/11/1998	Providing a social work service to clients with a learning disability, their families & carers. Supporting clients in day-care & supported living facilities & liaising with staff therein. Arranging respite. Empowering clients to access community facilities
South and East Belfast Health and Social Care Trust, Trust Headquarters KBHCP, Saintfield road, Belfast	Social Worker	12/01/1998	17/07/1998	Provision of social work service to medical cardiac wards at UHD. Providing a social work assessment to facilitate care planning & as an aid to discharge planning. Liaising & negotiating with families, community services, residential and respite units.
North and West Belfast Health and Social Care Trust. Trust Headquarters,	Social Worker	09/11/1997	09/01/1998	At MAH a key participant in the multidisciplinary assessment of clients with a learning disability

Glendinning house, Murray Street, Belfast				returning to live in a community setting. At Whiterock HC provided a social work service to community clients with a range of mental health difficulties
North and West Belfast Health and Social Care Trust. Trust Headquarters, Glendinning house, Murray Street, Belfast	Social Worker	18/08/1997	08/11/1997	Key worker to 35 members with enduring mental health difficulties. Co-ordinated and facilitate social & recreational activities and groups to enable members to improve their skills and confidence

3. I have been registered annually with Northern Ireland Health and Social Care Council since qualifying in 1997. I am part of a UK wide group of 6 Social Workers who provide a service to Patients with Haemophilia and other Bleeding Disorders. We have been meeting 2-3 times per year since 2017 to discuss common Social Work issues and provide peer support.

4. I can confirm that apart from the Infected Blood Inquiry, I have never been involved in any other inquiries

Section 2; Role as Haemophilia Social Worker

5. I have been the Regional Haemophilia Social Worker for people with bleeding disorders in Northern Ireland since April 2014. I have had contact with a number of persons with a bleeding disorder currently under the care of the Haemophilia Centre at Belfast City Hospital (BCH) who have contracted Hep C and / or HIV through contaminated blood products and continue to do so.

   I also provide social work support to children with a bleeding disorder and their families who attend the Haemophilia Centre at Royal Belfast Hospital for Sick Children (RBHSC).
   The support provided by me is detailed in my responses to questions 7 & 8.

   The senior staff members working in the Haemophilia Centre during my term of employment have included: Dr. Gary Benson (Clinical Director); Dr. Orla McNulty

(Specialist Registrar - now retired); Dr. Charlene Neil (Specialist Registrar); Dr. Chris McAuley (has since left post); Sister Collette McAfee (now retired); and Sister Helen Manson.

6 I am not aware of how my role as Social Worker at the Haemophilia Centres was created or funded and therefore I am unable to comment on these issues.

7. My responsibilities as Social Worker at the centres include –

- Providing a comprehensive social work service to users and families / carers of users attending the Royal Hospital for Sick Children and Belfast City Hospital. This will be at in-patient, day-patient and outpatient levels taking into account the unique range of supports needed by this group of people.
- Practising within the legal framework and within policy and procedural guidelines.
- Supporting families and carers of this client group.
- Identifying resources appropriate to the needs of this client group.
- Contributing positively to the development of services for this client group.
- Working as a member of the Social Work Team and Haemophilia Centre multi-disciplinary teams (MDT) across both sites.

8. Since April 2014 in my capacity as Social Worker at the Haemophilia Centres, I have provided advice to patients and their families in relation to practical and financial issues. I have and continue to help individuals cope with the physical and psychological effects of illness and treatment, manage family issues, establish contact with appropriate organizations and agencies, and manage transitions, as well as providing support and advocacy with work, education, benefits and housing issues. This has included patients who have been infected with and affected by HIV and HCV.

9. Prior to the introduction of the Infected Blood Inquiry (IBI) Clinical Psychology service in 2019, all patients including those people infected or affected with HIV and or HVC could avail of psychological support following a referral by the Consultant to BHSCT Health Psychology Service. In my role with patients and their families, I informed them of the availability of this service and, with their consent, then requested the Consultant to make an onward referral. Since the introduction of the IBI Clinical Psychology Service I advise them of this service and provide written information to such patients or families infected or affected.

In my role in the Haemophilia Centres, I provide 1-1 counselling and emotional support to people who have been infected with HIV, HCV and / or HBV, and to people who were affected by the infection of a partner or another family member. In addition, I direct and refer people to other agencies, e.g. GP, mental health services, voluntary agencies, etc.

10. As regards people who were informed they may have been exposed to vCJD, I am unable to say what counselling or psychological support was provided at the

Haemophilia Centres as those patients were informed prior to me taking up post in April 2014.

11. So far as the adequacy of arrangements at the Haemophilia Centres for Social Work, Counselling and Psychological support are concerned, I cannot comment on the situation prior to me taking up post in April 2014. Although there is no dedicated counselling service for the Haemophilia Centres, emotional support is provided by a number of professionals including Social Work and when necessary, referrals are made to specialist services as appropriate. Prior to the introduction of the current IBI Clinical Psychology Service in 2019, anyone who was felt to be in need of psychological support could, with their consent, be referred to the BHSCT Health Psychology Service.
    The current IBI Clinical Psychology Service has an efficient and effective referral pathway. There is a dedicated Psychologist employed within the service and there is regular liaison and communication with the MDT (Multi-Disciplinary Team). This clear communication between Psychologist and the MDT promotes and enhances the emotional wellbeing of all those persons attending. It has enabled the IBI Clinical Psychology Service to develop a knowledge and understanding of the complexities and issues associated with people who have been infected with HIV, HCV and / or HBV, and those people who were affected by the infection of a partner or another family member. As a consequence of this, the Psychologist has been able to build effective and positive relationships with those people and their families in a comprehensive and person centred manner. It has, therefore, provided those persons attending the Haemophilia Centre with excellent continuity of care and service provision. In my view, the current IBI Clinical Psychology Service meets the needs of those infected or affected,

12. Since being appointed in April 2014 it is my opinion that the Haemophilia Centre Director (Dr. Gary Benson) and all the senior clinicians (as listed earlier in response 5) who I have worked with have provided a very positive approach to the treatment of those with Haemophilia. In my experience, Dr. Benson and other senior clinicians have worked in partnership with the patients, their families and the Multi-Disciplinary Team.

    I am not aware of any patients learning that they have been infected while I have been in post. I consider the Haemophilia Centre`s arrangements for the care and treatment of those infected have been provided in a very sensitive and person centred manner.

    In my opinion the Haemophilia Centre, under Dr Benson`s leadership, strives to provide the highest quality provision of care to those persons infected with and affected by HIV, HCV and/or HBV and this is reflected in the centre`s policies and procedures and day to day practice. I believe that this is clearly evidenced in the 2019 Quality Review Service Peer Review Report on the Care of People with Inherited and Acquired Haemophilia and Other Bleeding Disorders (IABD), Belfast City Hospital.

    The Peer Review panel visited 37 sites in the UK which provided Haemophilia care to assess compliance with Quality Standards. The Northern Ireland Haemophilia Centre was noted to have a number of examples of good practice and achievements.

    At page 6, it was noted *"This team, with strong non-hierarchical leadership, was offering a very good clinical service and exemplary multi-disciplinary team (MDT) working"* and *"There was active patient and public involvement, with a formal survey, 'What matters to you', having been undertaken, and the team hosted a number of extra-curricular activities and events. Patients' feedback about the care they received*

> *was very positive, and they commented on the careful attention also given to families and carers."* (IABD Belfast Adults Final Report V1.1 2019). https://images.qualityreviewservicewm.nhs.uk/wp-content/uploads/2020/04/28121721/IABD-Belfast-Adults-Final-report-V1.1-20191219.pdf

Section 3 Impact on People Infected and Affected

13. & 14.

Relationships

From my perspective, I believe the biggest impact has been on relationships. People have avoided forming close personal relationships, some choosing not to have life partners while the pressure of living with uncertain diagnosis has contributed to relationship breakdown and many couples separating.

Impact on family relationships has been extensive. Fathers who were infected choosing only to share their diagnosis with their partners hence their children maybe never knowing or finding out following the Infected Blood Inquiry and in some cases after their father has passed away. Parents feeling extremely guilty because they unknowingly gave contaminated products to their child and are left with the burden of who to tell and run the risk of being blamed. Tension in sibling relationships whereby the siblings with the bleeding disorder were seen as being treated differently in the family.

The diagnosis has profoundly influenced family dynamics and elements of transgenerational trauma are evident today in my work with children with an inherited bleeding disorder.

Career / employment opportunities.

Individuals with a diagnosis often choose to be self-employed, which meant they could work alone. Others opted for part-time, casual, lower paid work, and often-moving jobs when ill or when employers began to ask "difficult questions" about their health, and when needing time off for hospital appointments etc. Many did not achieve their full potential in their career, turning down offers of promotion. Thus, many individuals' earning potential has been limited. Some people felt they were unable to work due to the fear / anxiety of having to disclose their health difficulties and relied on welfare benefits for their income. Some people were clearly unable to work due to their health difficulties and thus were also dependent on welfare benefits.

Financial

The financial cost of living with a chronic illness is well documented. However, for some people with a diagnosis they did not receive all the benefits which they were entitled to and many were, and still are, reluctant to avail of local welfare advice services, as they are frightened of being "found out". Concerns include having to disclose their diagnosis to a Benefits advisor or DSS staff working in an agency where someone may know them. This fear of discovery also manifested when Infected Blood Payment Scheme for Northern Ireland took over the management and administration of the Caxton, Skipton and Macfarlane Trusts. People became very anxious that a local agency would hold information about their diagnosis and required a lot of reassurance before consenting to their details being transferred to Belfast. Some individuals, for a variety of reasons, did not initially provide written consent and as such did not receive all the payments that they were entitled to.

In Northern Ireland the roll out of the transition from Disability Living Allowance to Personal Independence Payments coincided with the increased media and political awareness of the contaminated blood issues. People had been advised that they were on DLA for life but now they were being asked to complete a written application for PIP and attend for assessment as many saw it they had to prove their entitlement. The majority of our patients did not receive the benefit at this stage, many had to request a mandatory re-assessment and go to appeal before being awarded a payment which was frequently less than what they had previously received, some had to return their mobility car, some were not awarded at all and many gave up as the process took so long. There was a lack of specific independent welfare advice, as people were reluctant to use local advice agencies as they were concerned about confidentiality. The specialist HIV Welfare advice service did not have an understanding of Haemophilia.

Psychological

The issues I have identified have undoubtedly had a significant impact on "infected" and "affected" individuals' mental health and overall wellbeing and many were prescribed anti-depressant and anxiety medication. In trying to manage their emotional pain, some individuals used alcohol and other drugs as a crutch, a way of helping them cope, which brought added problems and difficulties for the individual and their families to try to manage. As a result of their diagnosis most individuals then made very difficult / problematic life choices and some have engaged in risky behaviours for the reasons highlighted; others having seen friends and family pass may think "sure why not - I`m not going to live long".

With increased media and political attention and the Infected Blood Inquiry, many people have been forced to review their lives, bring to the fore painful memories and family secrets which had been buried for a number of years and are again being re-traumatised. Children, who are now adults, are reviewing their experiences with this new information and current knowledge. They are revisiting the bereavements and losses they experienced when they were younger, reflecting on how this has impacted on their life - often evoking painful emotions and grieving for relatives and lost opportunities which is very challenging.

I think it is important to note that Northern Ireland in the 1980`s and early 1990`s was different to other parts of the UK. In certain areas in NI people tended to live, work and socialise in close-knit communities and this brought unique challenges for individuals trying to manage "the secrecy of their diagnosis".

Section 4; Trusts and Schemes established to Provide Financial Support

15. & 16. I cannot comment on what information patients may have received about organisations established to provide financial support prior to me taking up post in April 2014.

MFET or Eileen Trust - Since taking up post, I have not had any contact with MFET or Eileen Trust. As the only Social Worker in the Haemophilia Centre I was not aware of either of these organizations. I can only assume my lack of knowledge of these two organizations was due to them not being proactive in publicizing / or promoting their services.

I have informed those people who have been infected with HIV, HCV and / or HBV, and to people who were affected by the infection of a partner or another family member of the services these funds and trusts provide which are relevant to each individual's circumstances. I have provided information to persons regarding the Macfarlane Trust, Skipton Fund, Caxton Foundation and continue to do so with regards to the Infected Blood Payment Scheme for NI.

Macfarlane Trust - I have only had brief contact with Macfarlane Trust in respect of one patient. There was a small number of persons eligible for applying to the Macfarlane Trust.

However, it is my understanding that the majority of those persons did not wish to apply or avail of additional finances from this particular trust.

Skipton Fund - I have had contact with the Skipton Fund. My principal objective with the Skipton Fund was to clarify and ensure that eligible persons were registered and that accurate and up-to-date information was available to them. If this was not the case then it was made available to the Skipton Fund with the appropriate consent.

Caxton Foundation - I have supported persons with applications to the Caxton Foundation. I have assisted and provided guidance in completing their initial application. I have facilitated and directed the applicants in obtaining all the necessary evidence and documentation that was required to ensure their application would be successful. Hopefully, reducing the need for those persons to provide additional information repeatedly. With the person's consent I would have contacted the Caxton Foundation directly by telephone and / or email to ensure the application process was as effortless as possible for those persons applying.

When Infected Blood Payment Scheme for Northern Ireland took over the management and administration of the Caxton Foundation, Skipton Fund and Macfarlane Trusts, people became very anxious. The reason being reported to me was that a local agency would hold information about their diagnosis and required a lot of reassurance before consenting to their details being transferred to Belfast**.** Some individuals, for a variety of reasons, did not initially provide written consent and as such did not receive all the payments that they were entitled to. I provided the appropriate practical advice and emotional support person`s infected and affected during this period.

Infected Blood Payment Scheme for N.I. - I continue to support persons with applications to the Infected Blood Payment Scheme for NI in the same manner as noted above with both the Skipton Fund and the Caxton Foundation. In addition, I clarified with the person's consent that those registered did receive information regarding the transfer of Skipton and Caxton funds to IB Payment scheme for NI.

Overall, in signposting patients to these services, I have informed them of the services these funds and trusts provide relevant to each individual's circumstances.

17. Please note that I have answered this question previously in 15 & 16. In addition, the Haemophilia Centre did provide relevant information and documentation to support patients' applications, for example, supporting medical information. I would add that any requests I made to the MDT for the provision of additional medical information in the support of applications was provided in a timely and comprehensive manner.

18. I have been asked about involvement with the various Trusts and schemes below;

Macfarlane Trust - I had minimum contact with the trust in respect of one patient the applications to be registered were made before I came into post in April 2014.

Skipton Fund – I cannot comment as the applications to be registered with this fund were made and processed prior to me taking up post in April 2014.

Caxton Foundation - From April 2014 until November 2018, I supported approx. 10 clients with making applications. Some patients did not appear to be fully aware of the foundation and services offered. Compiling the initial financial information was quite time consuming. However, from what I can recall the majority of decisions were made in a timely manner. I can only recall one client being refused a grant following appeal and others were above financial threshold for top up payments.

Infected Blood Payment Scheme for Northern Ireland - The application procedure is quite comprehensive requiring detailed financial information which has discouraged some people from applying. The eligibility criteria to apply to the scheme is accessible. However the criteria for discretionary awards is less clear. Unnecessary repeat applications have not been a feature of the Scheme to my knowledge.

I have provided support to clients with applications for one off grants and for Income Top Up payments. I am aware that patients have made successful applications without my support. I supported one person through a very difficult Stage 2 application where he was quite distressed having been advised following appeal, that he did not meet the criteria for stage 2 payments. Applicants have positively reported their contact with the scheme and state they have been kept informed throughout the process. I think decisions are currently being made in an efficient and timely manner. To the best of my knowledge, I believe applications are decided in a consistent way. Moreover, to the best of my knowledge adequate reasons were given when applications refused.

Section 5 Effect on Clinical Staff

19. I am unable to say what occurred prior to me taking up post in April 2014. Since 2014, any infection control measures that were in place or subsequently revised were implemented Trust wide and were not solely for the Haemophilia Centre. However, with any particular medical condition there may be specific health and safety policies and processes to be adhered to. I am not aware, nor have any knowledge, of any practices that would have been considered discriminatory.

20. The BHSCT has detailed policies and procedures in place for reporting concerns or complaints regarding patient and staff safety. In my experience, the Haemophilia Centre and all staff comply with these policies and procedures. Additionally, BHSCT has a Whistleblowing Policy that staff can avail of. During my time in the Haemophilia Centre I have not had the necessity to report any concerns or complaints regarding patient and staff safety.

21. As a Social Worker, it is not within my role or remit to provide treatment to any patients. Patients who contracted infections from their treatment did so prior to me taking up post in April 2014.

Section 6 Other Issues

22. During my time as Social Worker in the Haemophilia Centre I have had numerous discussions, conversations and interactions with senior clinicians about matters covered in paragraphs 5 to 18 of this statement and / or within the Inquiry's Terms of Reference. It is an essential function of my role to liaise and advocate on behalf of those persons attending the Haemophilia Centre. Given the extensive and numerous interactions I have had with senior clinicians and other members of the MDT since 2014 in respect of the care of persons infected and affected, I would not be in a position to detail these individually. In answering this question, I have provided a broad illustration.

My role includes attending and participating in MDT meeting to discuss patient care and treatment plans. This would have often included matters noted in paragraphs 5 – 18. For example, I would have had discussions with senior clinicians about the provision of medical information to the various funds and would have requested onward referrals to the clinical psychology service.

I would have also had numerous discussions face to face, by telephone and email with senior clinicians regarding diagnosis and treatment plans. This enabled me to be more knowledgeable and better informed and therefore better placed to support and advocate for those persons with whom I was providing a service to.

I would advise the Haemophilia Centre`s MDT, which included senior clinicians, if I was aware of information regarding a person`s personal circumstances that may impact on their medical or treatment plans. I would have also informed and updated the senior clinicians if there were any risk management concerns I had become aware of.

In my interactions with senior clinicians in the Haemophilia Centre, I would have regularly informed and updated them of the focus of my work with persons infected with or affected by HIV, HCV and / or HBV. I have regularly informed and updated the senior clinicians of when I make an onward referral or signposted a person to other appropriate agencies.

It is my opinion that any discussions or conversations or interactions I have had with senior clinicians at the Haemophilia Centre have been essential. This has ensured that persons infected with, and affected by HIV, HCV and / or HBV have received an individualised and person centred care and treatment to a very high and equitable standard.

23. The only other point I wish to reiterate is some persons infected with and affected by HIV, HCV and / or HBV who I have provided support to in my role as the Regional Haemophilia Social Worker to my knowledge have not engaged with the Infected Blood Inquiry process on any level. I have therefore tried to ensure that my responses do not identify such individuals in any way or compromise their confidentiality and I would be grateful if this could be respected.

Signed: **GRO-C**

Patricia McGrath

Date: 11/9/20