Witness Name: Mary Carolyn Duggan
Statement No.: WITN4052001
Exhibits: -
Dated: 2nd August 2022

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MARY CAROLYN (CANDY) DUGGAN

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 08 April 2022.

I, Mary Carolyn Duggan, will say as follows: -

Section 1. Introduction

1. My name is Mary Carolyn Duggan, and I am also known as Candy Duggan. I was born on GRO-C 1952 and my address is known to the Inquiry. I live in GRO-C, Ireland. I am now retired, having worked as both a Staff Nurse, Health Visitor and Clinical Nurse Specialist in several areas across London. My professional qualifications are as follows:

    - RSCN
    - RGN
    - RHV
    - MSc Anthropology of Children and Child Development
    - Certificate in Marital and Family Therapy
    - Post Graduate Diploma in Health Service Management

2. I have held the following posts:

1995-2007 – Clinical Nurse Specialist at Redbridge PCT

1989-1995 – Clinical Nurse Specialist at Great Ormond Street Hospital

- 1984-1989 - Full-time Health Visitor, Assessor of Health Visiting Supervised Practice, locum Family Planning Nurse, Haringey Health Authority, G Grade
- 1977-1984 - Part-time Family Planning Nurse Islington Health Authority, part-time Health Visitor, Haringey Health Authority
- 1975-1977 - Full Time Health Visitor, Islington Health Authority
- 1974-1975 - Student Health Visitor, Islington Health Authority
- 1973-1974 - Staff Nurse, Great Ormond Street Hospital (GOSH)
- 1969-1973 - Student Nurse, Great Ormond Street Hospital (GOSH)/Hammersmith Hospital

As Health Visitor, my role was to support, monitor families mental and physical health wellbeing, monitoring child development, encouraging a health lifestyle, promoting immunisations, liaising with social services and Police re child protection. I undertook home visits and clinic visits.

As Assessor of Health Visiting Supervised Practice, I would be allocated a student Health Visitor and my role was to monitor their practice and to work with their supervising college, monitoring good and bad practice, and liaising with their supervisors. Essentially, my job was to ensuring their fitness to practice.

As locum family planning nurse, I worked alongside family planning medical officers, welcoming patients, and making them feel at ease. I prepared clinics, discussed forms of contraception, and assessed people's readiness to use contraception or not. I carried out home visits, and my role was to inform, educate and discuss what would be appropriate methods to limit childbearing within communities, if so wished.

As Staff Nurse at GOSH, my role was to provide nursing care to children, and support and information to parents and carers. I also monitored and supported junior nursing staff, and provided education about various conditions that the children were presenting with.

I had cross-spectrum training. As staff nurse, I had a particular post, mainly at '5CE', which was a neonatal ward for infants with mainly gastro-intestinal conditions.

3. In respect of committees and groups relevant to the Inquiry's Terms of Reference, I was invited by Sue Burr, Paediatric Nurse Adviser at the Royal College of Nursing (RCN) to set up and Chair a Paediatric AIDS Special Interest Group at the RCN. The group's purpose was to raise awareness and provide support and information about HIV infection in babies and children to paediatric nurses in the UK. I was a member of the RCN Nursing Forum and I also contributed to a chapter in the RCN HIV Nursing Guidelines. We met quarterly, and minutes were taken of the meetings although I do not have a copy of the minutes myself. There was an open invitation to any nurses who were interested in HIV or worked caring for families affected by HIV. This was in the late 1980s – early 1990s, though I cannot recall the exact dates.

4. I can confirm I have not been involved in any other inquiries or litigation with regard to HIV, HBV or HCV.

Section 2: Your role as a Clinical Nurse Specialist & HIV/AIDS Counsellor

5. I was employed at Great Ormond Street Children's Hospital (GOSH) from 1989-1995 as a Clinical Nurse Specialist/Counsellor HIV & AIDS, H grade. I was answerable to the Director of Nursing and to the Director of the HONDA unit, though I cannot recall their names. Other Senior Staff Members during this period were as follows;

- Dr Ian Hann - Consultant Haematologist
- Dr Michael Levin - Consultant Infectious Diseases
- Professor Roland Levinsky – Professor of Immunology Institute of Child Health (ICH)
- Dr Diana Gibb - Senior Lecturer
- Dr Vas Novelli - Consultant Infectious Diseases. Dr Novelli took over from Dr Levin during my time at GOSH.
- Rebekah Lwin – Psychologist for HIV and AIDS
- Susan Trickett – Senior Social Worker

6. My role was a 'joint appointment' between the Haematology Department and the Infectious Diseases Departments at GOSH. This was a new post which was created for me when I was appointed. The post asked for a paediatric nurse with an interest in counselling to work with families affected by HIV at GOSH. The role developed and expanded over time, starting with around 12 families which increased to approximately 50.

The main objectives were to provide pre and post-test counselling and psychosocial support to the families presenting to the Infectious Diseases Department at GOSH. We also worked with patients presenting to other specialties requiring HIV testing as part of investigations into differential diagnoses. We provided information and support and counselling about HIV and AIDS to families of boys with Haemophilia who were diagnosed with HIV, HBV and later, HCV. Parents were very aware of the public perception and stigma of those infections. We acted as a central point, liaising with other health and social care and voluntary agencies providing information and support regarding HIV. Additionally, part of the role was to coordinate HIV and Haemophilia outpatient clinics.

As a CNS I had an understanding of medical, social, developmental and psychological aspects of chronic disease. My role was key in providing, coordinating and directing the care of the patients. Offering knowledge of HIV infection expected course, prognosis, treatment choices and other support available to patients and families and health care staff. There was a CNS for haemophilia already in post. I can't remember her full name but her first name was Jenny, and then Kate Khair subsequently came into post.

The Palliative care team which, was part of the Oncology department, provided invaluable information and support about managing and helping to support families where difficult news was given.

7. In respect of the hierarchy, clinical decisions were always made by senior Medical Staff. Patients and decisions regarding their care were discussed at fortnightly multidisciplinary team meetings. These involved the relevant doctors, Nurse Counsellor, Psychologist, and Social Worker. If they were discussing inpatients, the meetings would also include the nurses in charge of the ward, dietetics department and the play specialist if appropriate.

   Dr Michael Levin created a supportive atmosphere, conducive to the sharing of information amongst team members. Clinical staff asked for our opinions regarding what we felt to be in a child's best interest. There was excellent, open and honest communication and decisions were explained to all staff. I believe this was the result of GOSH's long history of caring for families where children have chronic or life limiting-conditions. I have experienced very different styles in other roles in other hospitals.

8. The Multidisciplinary Clinic as referenced in my CV describes the coming together of Doctors, Nurse Counsellor, Psychologist and Social Worker, and if a child was an inpatient, as mentioned earlier, this would also include the nurses in charge of the ward and play specialist if appropriate.

9. My role of Chair of the Paediatric AIDS Special Interest Group at the Royal College of nursing, was as follows:

   - A clinician
   - An educator, educating nurse colleagues about HIV infection by formal teaching and through regular work together,

enhancing the development of nursing knowledge. I facilitated days about HIV infection in children including ENB 934 courses throughout London.

- As an agent of change enhancing service provision.

10. I worked with Dr Ian Hann, professor of Haematology and Oncology, at GOSH from my appointment in 1989 until 1995. Dr Hann, was passionate about comprehensive specialist care for boys with haemophilia. There was shared care between local hospitals and haemophilia centres as many of the boys lived a long way from GOSH. GOSH as a tertiary referral hospital provided teaching and mentoring about Haemophilia and other bleeding disorders across the UK.

The Haemophilia clinics were held as a one stop shop, including routine consultations with the dental department and physiotherapy. As the post developed, the decision was made that we needed to provide more support for whole families affected by HIV, as parents would often not go to their own appointments because their children came first.

The one stop shop was set up together with a consultant from James Pringle House, the sexual health clinic at Middlesex hospital. This was a relevant development for the boys with haemophilia and HIV, because as they got older, they would have to go from a very family orientated environment at GOSH to a sexual health clinic where they would have individual consultations without their parents present.

The one-stop-shop gradually introduced the boys to health advisors and eased them onto next stage. GOSH couldn't admit children after the age of 14, so we would generally start discussions around this age, as they would be moving onto other units as 'adult' patients.

There was difficulty in finding an appropriate venue for the clinic because of the stigma. Accommodation was found at GOSH outpatient clinic. The clinic was called ABC Clinic, and was not labelled as an HIV clinic again because of concern over stigmatising families.

There had to be cooperation between adult and paediatric services. GOSH had to have condoms, oral contraception, adult formulations of drugs. This was finally set up in 1991, as it took some time to get this in place.

Home prophylaxis treatment with FVIII had revolutionised the lives of young people with haemophilia, preventing joint damage, severe life-threatening bleeds, and allowing young people to attend school and have social lives.
I recall that Dr Hann was very strict, and was adamant that all clotting factors should be British, pathogen treated and recombinant FVIII when it was available.

The small cohort of boys was already infected with HIV when I came into post. I do not know how these patients, parents or carers learned that they had been infected with HIV, HCV or HBV. The boys initially were not aware of their diagnosis however, all the parents and carers were aware.

A high percentage of those tested who returned a positive result, as everyone who was tested was symptomatic.
Arrangements for the care and treatment of those infected was managed jointly by the Haematology, Infectious Diseases and Immunology departments.

Section 3: Knowledge of risk

11. GOSH's approach to the use of FVIII and IX concentrate was that they were only used on the basis of clinical need. This involved laboratory diagnosis, and considering the age of the patient and severity of the bleed.

12. I cannot recall the content of the policies relating to the use of blood and blood products. However, I am aware that there were policies in place. I do recall that all blood products were checked by two qualified members of staff. They would be checked against the patient's name, age, hospital number, blood bank ID number, against the blood product we had. There was a blood bank at GOSH. Clotting factors, cryoprecipitate, DVAPD, and any blood products which required refrigeration and monitoring, were all kept at the blood bank. FVIII would have been stored at the Haemophilia Office, which later developed into a comprehensive care centre.

13. My knowledge of the infection risks of HIV, HBV, HCV and vCJD was based on my training as a nurse and developed over time as new information became available. Information was sought from training updates and medical and nursing literature. All staff were required to use Universal Precautions in relation to exposure to blood and body fluids. This included essential practices of asepsis, avoidance of needle stick injuries, blood spillages, and safe disposal of clinical waste. Information about the risk of acquiring HIV and HBV needle stick injuries was available and again changed over time as experience developed.

GOSH had an infection control department and universal precautions measures in place, and we worked closely with the microbiology department to keep up to date with best practices, as information changed over time. We had a journal club every week in which relevant articles were discussed. A statistician scanned medical journals and publications and highlighted all of the relevant articles. This was informal, and was usually held on the ward. The incentive came from the top, it was started by consultants.

I was happy with the level of training and updates provided. GOSH was a huge learning environment.

14. I understood from information and training that all blood and blood products carried a significant risk of Transfusion Transmitted infections (TTI). For instance, the risk of transmission of Cytomegalo Virus (CMV) for patients undergoing treatment for leukaemia (bone marrow transplantation) was already known.

15. From the beginning, we knew there was a difference between domestic and commercial blood product, and we had discussions about risks. However, we understood the use of domestically sourced blood and blood products was also a risk, albeit a lower risk than those imported from the US. The policy at GOSH was to use British heat-treated products and these were replaced by recombinant concentrates when it became available and these carried no risk of TTI.

I believe that all parents were informed about the risks of infection. I don't know whether patients were told whether they were getting domestic or commercial blood products when they were treated with them. It would have been 'NHS factor', i.e., it would all have been supplied from NHS. We would only know by the labelling of it. If it was labelled as 'BPL', it was British. If it was labelled Bayer, Baxter, or Armour, we knew it was commercial. I don't think this would have been brought to the attention of the parents or patients.

Parents were regularly provided with boxes of FVIII to take home, so they would have been aware from the labels if they looked at them. One family had three boys with haemophilia. The amount of storage needed for FVIII for all three boys was a garage.

I can't recall any patients or families ever raising the issue of where a blood product came from.

16. Training and advice provided to clinical staff was provided by the Infection Control team, Microbiology and Virology staff, haematology staff and Infectious diseases staff. I cannot recall how often we were given updates. All staff were required to have a Hepatitis B vaccination. There was a lot of stigma and misinformation regarding HIV. Nurses were also exposed to negative publicity in the press, so people were initially very wary and frightened.

17. Blood was only used when it was deemed to be clinically essential. Blood was tested for pathogens including CMV. Senior clinicians were responsible for making these decisions.

Section 4: Testing and Treatment of Patients

18. Consent was usually given by parents and by young people deemed to have sufficient age and understanding. This would be written consent and an ongoing, continuing process. Written records of relevant conversations were kept.

19. I am not aware of any specific training in relation to obtaining consent. This was, however, part of my nursing training and continuing professional development.

One of the dilemmas was whether a child could consent to treatment, but could they consent to not have treatment? It was a very delicate situation, and was difficult for parents who had struggled to keep their children alive, to be faced with the potential situation of the child no longer wanting treatment.

If there was a conflict, there would be discussions with Social Workers, counsellors, psychologist, and the family.

GOSH's motto was "Child first and always". However, the child may not have had sufficient understanding of consequences, so that needed to be properly explored.

All children were encouraged to manage their own condition or illness, and they were generally wise beyond their years.

There was also a level of implied consent, in that if you had presented for treatment, there was implied consent for diagnostic practices and treatment.

20. I understand that consent was required for all blood tests. I am aware that stored blood was tested retrospectively. I do not know if specific consent was given for storage of blood samples.

21. All the boys with haemophilia were already infected with HIV when I came into post, and none were aware of their status. Tests for HCV became available in 1990 and this was communicated in person to parents at clinic appointments as soon as possible. Information was given verbally and in writing about the process, what negative and positive results would mean, and possible consequences of a positive

test result. Test results were given in person either at routine appointments or earlier at the request of the parents.

Pre-test counselling was important at the start of the process. The way the information was given, the quality of support and information given following diagnosis was all known to effect how well patients and families would cope in the future.

Most people's understanding of HIV was that it was AIDS. Parents generally did not want to tell their children they had HIV. Disclosure was highly anxiety-provoking for families.

There was often a conflict between the right of child to know vs the right of the parent to withhold information which would be distressing to the children. Secrecy was fuelled by traumatic experiences. For example, one dad said he had disclosed his child's status to close family members and had not heard from any of them since.

We generally felt that young people had more of an adult knowledge and understanding from age 11 onwards, and if they were told when they were younger, they would have fewer preconceptions. We had ways of talking to the children about medicines and viruses, without actually naming HIV.

The issues surrounding disclosure were constantly discussed within the team. Out approach was to work with the family towards a readiness to tell. We tried to facilitate clear, honest open communication. Parents were always encouraged to do the telling, but we would not lie to a child if they asked us direct questions.

22. Counselling and psychological support was available to all the families, either at appointments or when requested. This was ongoing, provided by myself, the psychologist and other clinicians. Families were also encouraged to access HIV voluntary services, however most felt that organisations such as The Terrance Higgins Trust were not suitable for them. A number of parents felt they couldn't even walk through the doors there, as they felt it was for gay men, and therefore not relevant to them.

Information and counselling were also available from the Haemophilia Society. Parents were often reluctant to take literature home as it might have been visible to family and friends and their sons, who might ask questions, or make assumptions.

There were no support groups for people with HCV at that time and we often received requests to talk to people from all over the UK who had been diagnosed with HCV for information about sexual transmission, risks of mother to baby transmission and the risks associated with breastfeeding.

23. Information was provided to patients by the Haematology, Infectious Diseases and Immunology departments. This included information regarding the risk of transmission to others, including sexual transmission. Parents found addressing whether their sons were sexually active a difficult topic, and support was ongoing. Diet, good physical health, and dental hygiene would be discussed. How, when and where to disclose status to others, who could support the family, managing medication, and adherence to medication when it became available, were just a few of the issues which would be discussed.

Written information was provided from the Haemophilia Society and Dr Peter Jones book "Living with haemophilia". There was little information specifically written for children and together with Rebekah Lwin and Dr Diana Gibb we wrote a booklet "HIV and AIDS in Children. A guide for the family". This was not aimed specifically at families affected by haemophilia but aimed to inform and to dispel some incorrect information.

Many families as I've said did not want to take any written paperwork or literature home, as they did not want to risk it being seen by visitors to the home.

24. When I came into post, there was no available treatment for HIV. Zidovudine (AZT) became licensed for use in adults in 1989.

The Concord trial (1988-1991) enrolled adults with HIV for immediate vs deferred AZT. AZT demonstrated a significant decrease in HIV associated morbidity and mortality, assuring normal growth and development, improving survival and quality of life.

Children and adults have a different therapeutic response to drugs. Pharmacokinetics is the study of a drug's absorption, distribution, metabolism and elimination. The effects of any drug, the way a drug enters the bloodstream, the way it is used by the body and the way the body eliminates the drug may be very different in children compared to adults, so often drugs for children lag behind those for adults.

Some of the boys with haemophilia took part in a pharmacokinetic study of AZT. I cannot remember the date. When AZT was given, all the families were asked to keep a diary of any side effects they experienced. My memory is that parents reported fewer headaches and some weight gain. This study would have been agreed by the Research and Development Department and the Ethics Committee. Parents would have had verbal and written information and opportunities in person to ask questions.

However, I recall a number of adults reported that AZT caused nails to darken in colour or even turn black. This was very visible, and caused further issues regarding stigma, as people were able to draw conclusions regarding a patient's HIV status from the state of their nails.

AZT was licensed for use in children in 1991. Wellcome formulated the drug in syrup form for children.

The benefits of monotherapy with AZT were found to last for approximately 18 months and following the Delta trial in adults, dual therapy with Didanosine (DDI) was recommended.

Over time, we were able to provide more information regarding the prognosis and treatments available. We always advised answering any questions from patients and their families truthfully.

There are issues with age specific adherence to medication, as well as psychological and sexual maturation.

Treatment for HCV became available in the form of Interferon and Ribavirin. I cannot recall if any of the patients were given this treatment. I do recall that Interferon was poorly tolerated and had debilitating side effects in adults including depression, leading to poor mental health.

25. Patients with HIV, HCV and or HBV were not treated any differently to others. If they had very low immunity they would have been 'reversed barrier nursed' to prevent them from being exposed to pathogens that might cause further illnesses.

Initially biohazard stickers were put on all samples, including blood and urine, however this changed over time and 'universal precautions' were accepted as the concept of 'risk' was explored.

Universal precautions should be followed for everyone, as they both avoid identifying children as risk and protect staff and children from blood borne infections, negating a need to know their status.

26. Clinical staff were made aware of a patient's HIV status if it was relevant to the holistic care of that patient. I am not aware of any protocols for notifying other staff.

Section 5: Research

27. Apart from what I mentioned in paragraph 24, I cannot recall any other specific research relating to HIV, HBV, or HCV. However, in 1991 PENTA trials (Paediatric European network in Trials in AIDS) was set up. This was a collaboration between paediatric HIV centres in Europe to coordinate prevention, diagnosis, care and treatment for babies, children and young people across Europe. The primary aim of the network was to undertake independent clinical trials to address questions about antiretrovirals in HIV infected children where answers could not be extrapolated from trials in adults. The PENTA 1 trial took place in 1994.

Trials would have been managed by the Infectious Diseases unit, Immunology and Haematology.

Dr Diana Gibb (now Professor Diana Gibb) was the lead clinician for the PENTA trials at GOSH.

28. I was involved in a small pharmacokinetic study of AZT in the boys with haemophilia. I will discuss this further in Section 8.

29. GOSH had a well-established Research and Development unit and an Ethics Committee and all research was submitted and agreed through these departments. Verbal and written information would have been given to participants and their parents/carers.

30. I understand the term 'PUPS' to mean 'Previously Untreated Patients', i.e., untreated with any clotting factors. Newly diagnosed patients would have been entered into trials of the new recombinant products. I cannot recall any trials being undertaken at GOSH. Our cohort of patients was all previously treated with clotting factors, as GOSH is a tertiary referral hospital.

Section 6: Impact on people infected and affected

31. All the patients at GOSH were children with HIV, HBV and/or HCV. In some families, more than one child was infected. When a child was infected, the whole family was affected. At that time, parents believed that HIV equalled AIDS, and that equalled death. This affected all areas of their lives. The fear of friends, neighbours, and schools finding out was overwhelming and that led to social isolation and a lack of much needed practical and psychological support.

Medication needed to be refrigerated and therefore might have been visible to visitors who might ask difficult questions. Drug regimens might have meant that medicines should be taken during school hours and fear of being found with their medication in school was another concern, particularly when the school was not aware of the child's HIV status. This caused a dilemma due to the risk of a boy facing punishment or having his status being disclosed.

As I mentioned, disclosure of HIV status was an issue. The philosophy at GOSH was that all children with chronic conditions should self-manage, make choices appropriate for themselves. However, when to tell a child and conflicts between the rights of the child and the readiness of parents to tell their child and continue to have supportive conversations were ongoing challenges. Many parents, again, did not want to have literature in the house that may mention HIV, for fear of awkward questions and of being ostracised.

Preparing patients for transition to adult services increased anxiety amongst parents regarding disclosure of their child's HIV status and we were concerned that insisting that children know about their status might result in parents/carers avoiding hospital appointments.

It was important that children with chronic diseases could self-manage, become independent of carers and be able to have the information to make informed choices.

32. All the boys were under 14 years of age. Living with Haemophilia often impacted on their schooling as they may have had interrupted school attendance in order to treat bleeds at home or for more serious bleeds, attendance at hospital, as well as having to attend regular outpatient clinic appointments (OPD). We tried to arrange appointments during school holidays where possible.

In 1994, there were public demonstrations about the use of AZT outside GOSH. Protestors chained themselves to the railings and aggressively approached people entering the hospital. The protestors viewed AZT as "poison". Moreover, intrusive press lied their way into outpatient clinics to try to gain access to patients and staff caused further distress and uncertainty which compromised treatment.

The inaccuracy of knowledge and negative attitudes in both health and social care staff as well as the general public stigmatizes and caused prejudice and fear.

I do not recall any difficulties in obtaining financial support for families.

Parents would have to take time off work to attend hospital appointments. I believe reimbursement of fares was available through the almoner's department.

Many families found it difficult to obtain travel insurance, which meant they were prevented from taking their children abroad. We used to refer families to a special insurance company, though I cannot recall the name.

Many parents wanted to take their children to Disneyland in the USA, but as well as the difficulty obtaining insurance, there were significant issues about carrying HIV medication into the USA. Families had huge obstacles whenever they wanted to travel. HIV positive individuals were required to have an identifying mark on their passports.

Only one boy with haemophilia died during my time at GOSH. I think this was HCV-related, not HIV-related. I remember another boy died of an AIDS defining illness. Undertakers refused to lay him out for fear of catching HIV. This was a regular occurrence, and would be incredibly distressing for the families.

There was one funeral company who we referred patients to as we knew them to be sympathetic and did not have issues with infection control, however unfortunately many providers did cause problems. If a child died on the ward, we would keep them on the ward for as long as possible to allow them to be visited by friends and family, before they were removed to the hospital mortuary. Once the funeral directors took them, there was often very little in the way of families being able to visit their children.

Section 7: Trusts and Schemes established to provide financial support

33. Families were provided with written and verbal information about The McFarlane Trust, Terrence Higgins Trust, and other funds available to all families attending GOSH, and were encouraged to apply to them for financial and other support. There were other trust funds e.g., Malcolm Sergeant Trust funds that were flexible in responding to requests for financial help.

Much of the information given was verbal, but there were many leaflets available. As I mentioned several times many families would not take them due to the risk associated with them being seen laying around at home.

34. Patients were assisted by the social work department and clinicians where appropriate. We did not have any issues obtaining financial support for patients.

One of the haemophilia nurses at St Thomas', Christine Harrington, made herself very available to help and support with applications where appropriate.

I feel the process was transparent and accessible. There were repeat applications, because they were for specific things. But nothing that I considered unduly bureaucratic.

35. I cannot recall if information was supplied to support these applications. I believe that this may have been the case to support the application. This was done with the consent of parents.

36. I have answered this question above and I am not able to provide any further information regarding the application process.

Section 8: Effect on clinical staff

37. Universal precautions were paramount in respect of managing needle stick injuries and exposure to blood and blood products. Policies were developed together with the hospital Infection Control team. Members of the Infectious Diseases Department, Haematology and Immunology were available to discuss individuals' perceived risk, management and preventative treatments when they became available.

When a child with HIV died, normal universal precautions were observed laying out the body, however, parents and carers were encouraged to spend as much time with their child on the ward as funeral directors would sometimes not allow viewing of deceased children with HIV, because of fears of transmission to workers. This compounded the grief and isolation for families.

38. I did not report any concerns or complaints.

39. See section 8.

Section 9: Other Issues

GOSH already had expertise in giving difficult news to families of children with life limiting and chronic illness.

When starting in post, parents' understanding of HIV was that HIV equalled AIDS, equalled death. Most of the parents did not want to tell their sons of their HIV diagnosis, as one father said "With all due respect, Candy, I understand what you are trying to say but my son will be dead before he ever has to know that he has HIV".

He described disclosure as one of the most anxiety provoking and frightening prospects. There was conflict about the right of children to know and to consent to treatment to protect themselves and others and choose who should know versus the right of parents to decide what was best for their child and withhold information that they felt would distress their child. This ethical dilemma was ongoing and discussed by all team members. I strongly believe that children have the right to know their own diagnosis but as a team we felt it was not in the best interests of the child to force an issue or to insist on disclosure or at a particular stage or age. We worked with the family achieve a state of readiness to tell and to identify and put in place help and support required following disclosure.

Counselling was a way of informing, facilitating, preparing and supporting the family. At that time children and young people under the age of 16 could make decisions about their own health needs if they had sufficient age and understanding. Information was given appropriate to their age, knowledge and developmental progression. We tried to facilitate clear, honest, open, communication of information. This was an ongoing process.

FVIII had led to home-based care and HIV infection brought them back into the medical model, we tried to aim for minimal intervention by the health care team whilst providing support and resources for parents in caring for their child/children and reducing the feeling of being different and achieving a normal a life as possible. However, the demand for confidentiality and secrecy was an obstacle to therapeutic support.

There were no support organisations at that time specifically for children with HIV. THT was supportive, based close to the hospital and they were happy to see parents and their children.

Secrecy fuelled by fear of breaches in confidentiality, often led to families experiencing social isolation. As I briefly mentioned earlier, one father said in tears that following disclosure of his sons HIV diagnosis, to close family members, they had not contacted him since – not even to ask how his son was. The shock responses of shock, anger, denial and depression commonly seen following trauma sometimes can take years to resolve.

40. When working as CNS HIV in Redbridge, I was involved with the care of 2 adult patients with HIV and HCV. One young man died at home and was cared for by his parents. The second died at the Mildmay Mission Hospital where he had regular respite. He was very isolated from his family and few friends as he feared being ostracised by the community in which he lived.

We received some stigma personally. When I started working, I had children at junior school. I talked to them about me going to work with people with HIV, and prepared them for if it was discussed at school, and what they might say, and how they felt. It was a concern for me in taking the post.

I rarely said what I did at social events. Either I would get a tirade about 'those sort of people' who got HIV, or people would walk away from me. It was very difficult.

The impact on staff could be challenging and upsetting. I felt I was fighting the corner of those infected, so I would at times deliberately try to challenge perceptions.
In my experience, staff were always looking for best outcomes, not necessarily as a result of policy and procedures in place, but working collaboratively in order to achieve best outcomes for families under our care. It was very important to us.

41. Publications are as follows:

- Lwin R, Duggan C. (1996) *Children with HIV & AIDS: Challenges for the Family & Professional.* Clinical Child Psychology & Psychiatry. Vol.1 (1) 45-48

This article outlines the psychosocial impact for families livening with HIV/AIDS and has particular relevance to the inquiry.

I have contributed to the following articles:

- O'Doherty M.J, Thomas S.H.L, Gibb D.M, Page C.J, Harrington C, Duggan C, Nunan T, Bateman N.T, (1993*) Lung Deposition of Nebulised Pentamidine in Children.* Thorax 48:220-226
- Gibb D.M, Duggan C, Lwin R, (1993) *The Family and HIV*. Genito-Urinary Medicine.67;5:363-366.
- Duggan C. (1994) *A Family Affair: Multidisciplinary Care for Children and families with HIV/Aids*. Child Health, June/July 1994 33 -36
- Duggan C. (1995) HIV Infection in Children. In*, The Nursing of Children. A Resource Guide.* ENB Update 1995.
- Lwin R, Duggan C. (1996) *Children with HIV & AIDS: Challenges for the Family & Professional.* Clinical Child Psychology & Psychiatry. Vol.1 (1) 45-48
- Duggan C. (1996) *HIV Infection in Children.* Paediatric Nursing Vol.8 No.10 December 1996.

I have written chapters in the following books:

- Gibb D.M Duggan C, (1993) Aids in Children, in: *Growing Up - a Young Person's Guide to Becoming an Adult*. Merlion Publishing Ltd.
- Lwin R, Duggan C, Gibb D. M. (1993*) HIV & AIDS in Children. A Guide for the Family*. Second Edition. The Hospitals for Sick Children and Institute of Child Health (booklet)

- Duggan C, (1994) *HIV* & AIDS. In: *Care of the Dying Child*. Ed. A. Goldman. pp 42-51. Oxford University Press.
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Statement of Truth

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

Signed **GRO-C**

Dated 2nd August 2022