I am Dr. Michael, Lawrence, Nesbit Willoughby, d.o.b: [redacted]

Qualifications:
MB,BS (Lond) 1950;
BA (Camb) 1953;
MD (lond) 1960;
MA (Camb) 1960;
MRCPath (UK) 1965;
FRCPath (UK) 1977;
MRCP (Glas) 1982;
FRCP (Glas) 1983.

Career:
I studied Medicine at St. Mary's Hospital Paddington. After graduating in 1950 and holding a London hospital house appointment I received an MRC grant to attend Cambridge University in 1951 to 1953 to study Biochemistry, and was accepted at Magdalene College. Following this I did my National Service in the RAMC from 1951 to 1953. In the second year I was posted to Hong Kong to work in the MRCP Sprue Research project and to run the army pathology service based at Kowloon General Hospital and at Hong Kong Military Hospital on Victoria Island. I was promoted to acting Major.
On returning to UK I was appointed to work in the St. Mary's Hospital Professorial Medical unit 1955-56, and then in the Professorial Microbiology Department as temporary Lecturer 1956-57. This was followed by 3 years as a registrar in haematology at the Radcliffe Infirmary, Oxford, working with Rosemary Briggs and Professor Macfarlane, world leaders in Haemophilia and Christmas disease, (1957-60). I then moved to Glasgow, firstly as a senior registrar in haematology at Southern General, Govan, (1960-63), until my appointment at Royal Hospital for Sick Children, Yorkhill in (1963-1982).
I moved to Perth, Western Australia, and commenced work as Director of Paediatric Haematology and Oncology at Princess Margaret Hospital for Children (PMH) in Jan. 1983. During my time there our unit was elected to be an overseas member of the USA Children's Oncology Group (COG). I retired from PMH on my 65th birthday (4/8/1992) but continued my activities in COG research, including chairing a committee on leukaemia relapse, for a number of years, but without day-to-day clinical responsibility. My only continuing medical activity is attending some report sessions at the PMH department from current COG meetings.

I have been asked to provide this statement by Tracy Tornbull at the Central Legal Office. I have had to rely predominantly upon my recollection of the era.

I was appointed as Consultant Haematologist to establish a haematology department at Yorkhill Royal Hospital for Sick Children and Queen Mother's Maternity Hospital in late 1963. Initially my responsibility was to set up a department able to perform the necessary haematology tests to diagnose and manage blood disorders.

In addition, there was developing a topic of great interest in this field, namely the hope of making steps towards the cure of some children with leukaemia. I had been fortunate to attend an International Haematology Conference in Lisbon a month or so

before my appointment where I heard a presentation by a Dr. Wolf Zuelzer, a leader in this field in the USA (Zuelzer, W.W.: Implications of long-term survival in acute stem leukemia of childhood treated with composite cyclic therapy. Blood, 24, 477, 1964). I contacted him personally regarding details of his treatment, and subsequently regarding management of individual patients; and later came to know him as a professional colleague during his visits to Europe. Over the following years management of childhood leukaemia and related clinical trials became my main focus of interest, although, as head of department, I also recognised my other responsibilities.

Around 1979 I heard from one of my junior staff (Dr. Anna Pettigrew, then a registrar I believe) and another registrar who had rotated back from Glasgow Royal Infirmary haematology department that they had developed a 'Home Therapy' program for their adult patients with haemophilia, and that this was proving highly beneficial in their management. Dr. Charles Forbes (a Consultant haematologist I believe) was involved, and he encouraged me to try to develop a similar program for our children. We had an informal 'team' involved with Haemophilia and Christmas disease (a similarly inherited Factor IX deficiency, but usually less severe) management and follow-up, including an orthopaedic surgeon, dental surgeon, haematology nursing sister, as well as haematology department medical staff. Although one could anticipate greater difficulties, compared to adults, in teaching parents to handle the necessary therapeutic blood products and to learn how to give intravenous injections to their children, we decided to attempt this. These unfortunate children often missed school to attend hospital for a bleed, could develop progressive long-term joint dysfunction, and could not usually enjoy any sporting activities, especially for those with more severe forms of haemophilia.

If such a patient was admitted to hospital for treatment they would usually be given cryoprecipitate as the source of FactorVIII. It is my recollection that one or more bags would be taken out of a deep-freeze, carefully thawed out in a 37 degree water-bath, and injected via an IV blood drip hanging from a transfusion stand in the ward.

We wanted to make things as easy as possible for the parents. So, for home therapy, we used a commercial source of Factor VIII (Hemofil I believe). This was ordered through the hospital pharmacy, as were the drugs we used in leukaemia etc. It proved relatively expensive but we thought its advantages justified this. It was much easier to reconstitute with its diluent, taking only a few minutes of gentle handling, as I remember it. The volume for a normal dose could be comfortably drawn up into a 10 or 20ml syringe, which could then be easily attached to a slender scalp-vein IV needle for injection (rather than requiring a drip-stand etc.).

When setting up this program, one of us, initially usually myself, went through all these points with the parent and child there together, as they practiced each step. Other medical staff also took part. There would probably be around a dozen or so training sessions, latterly often conducted by the haematology nursing sister. It was no easy matter getting the young children to let their parents give them an IV injection, but using small scalp-vein needles helped. Finally the family were sent home with a hand-written sheet which gave their weight, intended dose in factor VIII units, instructions regarding when to give a dose, eg: Firdays and Mondays for very severe cases, or in milder cases: "If there was a painful/swollen joint, any bleeding longer

than ½ hour, any deep bruise/swelling of head or neck, including tongue. If in doubt, give the dose". Then "If a reaction: give 10mg. (1 vial) of Piriton IV, and let us know". Also there were columns for date, units, batch number, and any problems or complaints.

I think it would be fair to say that in most patients their quality of life improved to an unrecognisable degree, with a number playing football at school. I personally thought it was proving one of the best things we had set up, and I think the others involved felt the same.

We had no idea that we were exposing these patients to serious viral diseases. I believe that problem only started coming to light in around 1983, after I had left the UK.

I hope some of these points may help the inquiry.

Regards,

Michael Willoughby