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Royal College of Physicians Oral History Project

Interview with: Christine Lee

Date: 2nd June 2015 and 26th June 2015

Interviewer: Lynda Finn

[PART ONE]

Q: This is Lynda Finn interviewing Christine Lee on the 2nd of June 2015 at her home, for the Royal College of Physicians' oral history project. Christine, can you tell me your full name?

A: My full name is Christine Ann Lee.

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Q: That you were wasting--, you would be wasted on medicine. Tell me more about that.

A: Well I think, erm--, I think that people who did pure science, and particularly at that time biochemistry was pretty new science, regarded medicine as rather a simpler option really, a less scientific option. I mean I--, looking back if--, the idea--, but of course time is always a constraint, but to do medicine if you had the time to actually do--, to have done your pre-clinical with your anatomy and things, er, and then to have done--, the biochemistry degree was four years so probably a really good way would have been if you'd spent two years and got your anatomy and physiology under your belt and then done two years and actually got a degree in biochemistry and then gone on to do your clinical, but I mean that option wasn't there. But I--, so I think--, I mean what actually happened was I--, the biochemistry degree at Oxford was exactly the same as the medics apart from the fact you didn't do anatomy and instead of anatomy you did much, much more chemistry. So I did two terms and then I wanted to change in the third term. My tutor was super, I mean because in those days actually Oxford had ten women and they were pretty strict about not allowing more women, but she--, I guess she negotiated it, maybe she said I was capable, I don't know. And so what I had to do I--, she said, "Look--, I mean normally in medicine what you did at Oxford you did your first year and then you did two terms and then you took what was called first BM which was anatomy, physiology and biochemistry and then that was your second year and so then you started on your degree course in the summer term of your second year and the three terms of your third year and you got a degree in physiology and then you did six months of pathology and bacteriology and then you went on to the wards. So it was three and a half years. So what my tutor suggested doing and which was actually brilliant, I--, she said, "Look, you should get under your belt a thing called prelims at the end of your first year and then if you were to fail your BM you could still take your degree." So I did the prelims, I think I did that in chemistry, physiology and biochemistry or something in--, at the end of the summer term of my first year as well as I had started anatomy that term. And that was quite hard work but it was--, in retrospect it was probably really good because I really consolidated that. And then we--, there was a tradition at Oxford that you went and did one kind of part of anatomy in Bristol in the summer holidays so that the term when you took your exam you didn't have to spend time doing dissection. So I went to Bristol for three weeks I think--, what did I dissected an arm I think in Bristol. And then, erm, in my second year at Oxford I--, the whole year I was doing anatomy, physiology and biochemistry and the normal people would have been taking their first BM at the end of the second term but I took it at the end of the holidays at the end of my second year. And then instead of doing the pathology and bacteriology after my degree I did it then and then I spent four terms doing my degree. So in the end I spent six months longer than I would have done and it--, but it was good. I mean in the end. And I mean the only--, the only kind of thing I sometimes regret but I think, you know, if you're a woman time is not really on your side--, I got a first and I think, you know, out of our year there were--, there were about 110 people so something like five people got firsts. So it was quite--, in those days it was quite--, it was quite a clever thing to do and I could have gone on to do a research degree then and I sometimes wonder whether I should have done that but it probably would have been a mistake because, you know, medicine is a long time. Anyway, then I--, boyfriends had quite a big part in my life because, erm, there was the one who got me to do biochemistry [laughs] who ceased to be a boyfriend shortly after that. Well not shortly but some time after that. I then--, when I was at Oxford when I was doing my finals I had a boyfriend who was doing research in physiology there and I had got a place at St George's in London but I decided to stay on at the Radcliffe and that was the best decision I ever could have made. I mean the training at the Radcliffe in those days was brilliant because it was so small, there were about 15 in--, 15 twice a year so you got to do so much. It was absolutely brilliant. Your experience was second to none. I mean when you were--, when you were on call for emergencies and things you were actually doing stuff. It was brilliant. It was absolutely brilliant and although actually at that time--, so I was there between '66/'69. Did I--, wait I minute, I can't--, I've forgotten when I qualified. I qualified in '69, didn't I? Yeah, '66/'69. At that time, you know, the Radcliffe was not considered particularly good, you know, it was still the real glory days of London medical schools and people who did Oxford and Cambridge degrees all went to London, you know. Well I don't think Cambridge even had a medical school then, but staying at Oxford to do your medicine was kind of [laughs]--, anyway, I was actually a scholar there and that was another funny story actually. At the time that I started we had an American professor called Paul Beeson who was quite famous in his day, he's dead now, and I always remember at the interview, I think this must have been the scholarship interview, he said something like, erm--, no, I said--, he said, "Why don't--, why aren't you doing--, why aren't you doing research?" or something like that. So I said, "I wanted to get--, no, "I wanted to get the studying done first," and he sort of laconically said something like, "Ah, so you think the studying is going to stop as soon as you qualify [laughs]?" or something, but he was really funny. He--, you soon learnt that one of his--, when we were on his firm one of his pet subjects was alcoholism so as soon as you learnt about the side effects of alcoholism you were all there and the other thing was he'd done research on [coughs] a thing called subacute bacterial endocarditis and again as soon as you got--, realised that and got all the answers to that he thought you were terrific. He could never ever get his head around the fact that British medical students, particularly those at Oxford, spent most of their summer term playing cricket. And he used to have these really sycophantic American students who used to come over and they used to be on the ward from about nine o'clock in the morning till midnight and he couldn't understand why the British chaps were slurking off to the cricket pitches or else and swanned in at kind of ten o'clock in the morning if you were lucky. He could never get his head around that.

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Q: We were talking about the Royal Free.

A: Yeah, the Royal Free that's right, this man who'd bied himself. So that job was incredibly busy but very good experience. Basically it was the combination of people who were long term on haemodialysis and people who were going into chronic renal failure and also people who were in acute renal failure. There were two--, there was a policeman who we completely got back from a terrible motorbike accident, he'd gone into renal failure. He walked out of hospital. And there was a woman, she wasn't a particularly inspiring lady, but we got her back from some awful renal failure that she had after a gallbladder operation I think. I mean the other thing about that, which in my life story is quite funny, was that it was--, the dialysis unit it was at the Royal--, the Lawn Road Hospital which was in Pond Street which is where the new Royal Free is and when I was there the renal unit was underneath a--, I don't know, a 12 storey block which housed nurses and junior doctors and it was a modern building. And it was attached to an old--, it was an old fever hospital actually, they had two--, the ward blocks were two wards one on top of another connected by this long corridor that was windowless and it went uphill and we had the women were on the ground floor at the top of the hill in the ward block and the men were down the bottom of the hill. But if people were on the ward above they literally had to be carried downstairs in chairs [laughs] if they needed investigations. I mean it was extraordinary. So if you had people with peritoneal dialysis they would be on the ward and they were old Victorian wards. Now that's been--, the old--, the new Royal Free was alongside it at the time that I was working there enveloped in plastic covers. I mean it was an edifice, it was up. The children that we looked after were in a delightful hospital that was at the top of Pond Street, it's been pulled down now, it's now kind of the car park at the Royal Free. It was a delightful hospital and it was particularly memorable because you know we had bleeps in those days but in that hospital you had lights, so when you went down the corridor there were four--, I think there were four lights and depending on the order or the number that they were flashing that was your bleep. And the children were on that ward. And, erm, subsequently that hospital was pulled down and the children's hospital was pulled down and that became the Royal Free Medical School next door to the new Royal Free. And I ended up when I was a consultant working in the haemophilia centre, which was basically on the site of the women's ward that I'd worked for when I did this renal job. No, it was--, it was--, it was an amazing six months but it was quite stressful. I mean some really dramatic things could happen. I mean the other thing that happened was that in those days if you had hepatitis B--, I mean now we talk about hepatitis B surface antigen but in those days it was called the Australia antigen because it was discovered in Australian Aborigines, but it was a marker of hepatitis B. And of course a lot of these patients because they'd had blood they were actually positive and there's a thing called e-antigen where you're really super, super infective. And those people we used to have for dialysis they had a rubber tube that went into an artery and into a vein and you went into that tube. Not rubber, plastic. And that sometimes got clotted and if it got clotted you had to inject Heparin to unclot it and the ones--, there were about three who were e-antigen positive and the job of unclotting them was left to the senior house officer. [Laughs] And you had to go in a special room and you had to gown up because around that time shortly before I did that job I think there had been at least two doctors in Edinburgh who'd died of hepatitis B. And there's one woman who was e-antigen positive who was--, her shunt was forever getting blocked and it was awful. And I used to have alternate nights off and I used to--, on my alternate night off I used to take all my clothes off and I used to always look at my sclera in the mornings [laughs] to see if they'd gone yellow. It was quite stressful that. I'd forgotten about that. Erm, what else about--, that job was amazing actually. And it was after that, after I'd done that job I got married.

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Q: Why do you think--, I mean how did you feel when you failed the exam earlier?

A: Awful, absolutely awful. I mean I--, because I never failed things and no, it was awful. And it was also an awful time because it was quite, you know, when you've got toddlers and then my father had died and my mother was not really well. She was also--, she ended up [laughs]--, she was lovely my mother, I mean she was fantastic, she ended up--, she outlived all the other grandparents, she lived with us for 15 years in the end and by then she had both knees, both hips and an ankle I think were all metallic, but roundabout the time that I was doing this she had a knee--, no, her knee was giving up and then she had a knee replacement. It was not--, it was not an easy time. I mean I have to say that--, I mean I suppose the two people in my life who in the difficult times, when the chips were down, were Roy and my mother. I mean my mother--, my mother came from a pretty poor background and she was bright but she had to leave school at, you know, 13 or 14 or whatever they did in those days, but she--, she was the person who, you know, don't give up, you know, she was always there. But it was not an easy time. But I kind of fell on my feet in the most extraordinary way. I got, finally on the fourth go, my MRCPath in 1982 and I applied for a couple of haematology jobs because by then Roy was a consultant at St Thomas'--, the Royal Free, and we were firmly established in Richmond. And I applied for a job at St Helier mainly because I was told to but I just hoped I never got it [laughs] I was so pleased when I didn't get it, but there was another job which I would have quite liked which was the old St Stephen's Hospital which became Chelsea Westminster I just didn't get it but I would have quite liked that job. But then after that, you know, there were no jobs on the horizon and then Peter Flute, this professor who was a nice guy, he handed me this piece of paper about a research job in the haemophilia centre at the Royal Free and scribbled across the bottom 'what about this?' or something. And that was fantastic. So I went for it. I mean I was--, I'd been a senior registrar in haematology for six years I think and there didn't seem to be any jobs coming up and this looked fantastic and it was fantastic. It was amazing. And the Royal Free haemophilia centre had been opened--, the new premises had been open for about four years then and the project was actually to work on non A non B hepatitis in patients with haemophilia. And what is quite extraordinary, this was 1982/'83, my colleagues at St George's said things like, "What is that? What are you doing that for?" of course we now call it hepatitis C. Anyway, I went off in January 1983 and they were very accommodating, I think I worked four days a week. Actually I didn't say that. Did I say that I worked part time when I was doing--, sorry, I--, sorry I skipped, didn't I, a bit? The part time scheme was called HM69 6 and when I went to work at Hyde Park Corner St George's that was under the scheme and you worked--, you had to work at least five tenths. In fact I worked six tenths and the department got that salary so that didn't have to come out of their regular salary. So all my haematology at St George's that I'd been working part time. Then when I got this research post I worked four days a week. Basically I think the amount of money--, they had an action research grant, action research for the crippled child I think it's called. It was then. I think they miss out the crippled child now. And, erm, [pause] so I worked there four days a week I had one day off and they were also pretty accommodating because they used to let--, I used to go in at ten o'clock in the morning so I dropped the kids off to school. And what was extraordinary about it was that it was to work on non A non B hepatitis but it was the beginning of HIV and, er, so everything changed. I was just looking at the time, would you like a cup of coffee or something? What do you want to do?

[END OF PART THREE 00:16:45]

[PART FOUR]

Q: This is part two of Lynda Finn interviewing Christine Lee on the 26th of June 2015 for the Royal College of Physicians' oral history project at Christine's home. Christine, let me take you back to what we were talking about last time. It's 1982 and you'd just started your job at the Royal Free. Let's talk about that.

A: Well this was an action research fellowship and it was originally entitled to look at hepatitis in patients with haemophilia, particularly what was then called non A non B hepatitis but is now referred to as hepatitis C. And I had responded to an advertisement that had been circulated in London to various haematology departments and I had completed my training in haematology and I thought it would be good to do a period of research and get an MD because it wasn't obvious that there were any consultant posts on the horizon and we certainly couldn't move from London because my husband had a consultant job in London. It was an extraordinary time. When I went there my colleagues at St George's Hospital where I'd been working thought I was completely mad because nobody knew what non A non B hepatitis was. It wasn't something that people talked about very much and in fact I think I only found one textbook before I went there to read up. And, er, they really couldn't understand why I did it but, as it happens, it couldn't have been a more significant and exciting time because during--, well it was at the end of 1982 the first cases of this strange new immunodeficiency syndrome had appeared in people with haemophilia. Now initially it was never linked to blood product and there were all sorts of suggestions that maybe these patients were gay, or maybe--, it wasn't really clear what was happening. Now, my primary task when I went there was to follow up patients with haemophilia who had had their first treatment ever with a large pool clotting factor concentrate, that's factor VIII or factor IX made from plasma of thousands of donors. And there were some patients, particularly those who had not such severe haemophilia, so when they had an operation they'd had a first exposure and we had very clear data on it. Most of the patients who had really severe haemophilia had already been treated many times so they weren't the ones being investigated. And non A non B hepatitis is very difficult because it's--, in most patients it's asymptomatic and the only way you can catch the infection is to measure the liver enzymes every two weeks for three months after they've had the first infusion which would have given them the infection. It was then--, they used to describe it as a yoyo transaminitis, in other words the enzymes went up and down. So my job was to follow up these patients and they were quite well, they just, you know, some of them had had an operation, some of them might have had some trauma which was why they'd had it, but I used to see them, take the blood and then that was tested and we also used to store it. And then eventually this resulted in a very significant publication that wasn't--, it wasn't actually published till 1985 although it was presented at various meetings from 1983 onwards, but the significance of it was that 100 per cent of people who received a large pool plasma derived clotting factor concentrate, whether the plasma came from British donors, that's National Health Service, or whether it came from commercial donors, which in those days were mostly American, they would get non A non B hepatitis. And at the time, you know, people were surprised. I mean now [laughs] it's obvious because we know now that the carriage rate in the general donor population of hepatitis C was about one in 300 so if you were collecting plasma from 10,000 people it was inevitable that patients would get this problem. The importance of the research at that time was because there were beginning to be concentrates that were heated which destroyed the hepatitis and because this research had been done it meant that when you introduced these new treatments you didn't have to do what we normally do in clinical medicine which is a controlled experiment because you already had your historical control that 100 per cent of people would get hepatitis. So the newer concentrates as they introduced new heating and additional steps you could always compare it to this gold standard. The other thing is, and I'll go forward in time with hepatitis because I think it probably makes it clearer and then I'll go back to talking about HIV which was going on alongside it, the patients didn't really--, weren't really aware of anything because they were mostly asymptomatic. And it was quite difficult to explain to patients what they'd got when you didn't even know what they'd got because we didn't--, the virus hadn't been identified and we hadn't got a test for it and it wasn't identified until 1989 and the first testing came in 1991 for antibody and then a little bit later, I think 1992/'93, you could actually measure the virus. So in the context of today we have patients going around saying, "They never told us anything. They never told us but they knew and we weren't told till 1991." And of course it's very difficult for them to remember we would have been talking about them having abnormal liver function tests, but we don't know what this means and you're very well and all the rest and it wasn't until 1991 that we actually told them, "Well actually you've been infected with hepatitis C." The other important thing historically which also, you know, is very different in the climate of today, was every time our patients with haemophilia came we collected a sample which was stored in

our deep freezers. We didn't ask their permission although I think we probably told them what their blood was being tested for and that we were storing it but that, you know, probably didn't mean much to them. I mean in the present day you would have to take consent and that's another issue that now is very problematical because later on we went on to use these specimens to test not only for hepatitis but HIV and the patients today are complaining that we did that without their consent, which clearly we did [laughs] but--, so the--, the hepatitis was actually what the grant had been obtained for me to do my MD. And then alongside all this comes this strange immunological problem and I used to look after the patients as they presented. You know, I was--, although I was a pathologist by training I had done a lot of general medicine and I was quite a good physician and they were presenting with strange infections. I mean I can remember in particular the oldest patient we had, he was 85 at the time I was looking after him, and I was looking after this strange pneumonia and testing him for things like tuberculosis, glandular fever, all sorts, he had this mottled lung and I couldn't find anything and eventually he died. Well what he obviously had in retrospect was he--, I mean we found out later from stored specimens that he had HIV. He had pneumocystis but we didn't know that. There were other patients who were seroconverting under our nose although we didn't--, I can't actually remember observing clinically a seroconversion illness although we did--, we could read in the notes of the very first patient who got HIV in 1979 when you actually carefully went through his notes you could see the seroconversion illness was being written down about and people thought he had glandular fever and all the rest. So I was seeing these patients and gradually the Haemophilia Society and, you know, haemophilia in the world is very international, it's a very rare disease and it's very organised. So there were things coming out from the World Federation of Haemophilia and the Haemophilia Society in this country. I mean one of the--, well there were several issues that we were really on the forefront of. There was the sexual transmission issue and very early on we issued advice for our patients to use condoms. You know, that became part of your clinical discussion. The other thing we did the Royal Free has a very big homosexual population around it, always has done, and we had this experience in the centre of looking after these patients in a climate nationally of great fear, you know, people were afraid to touch them, people thought you were going to get AIDS from lavatory seats, there were all sorts of things going on. And our laboratory were the first to use gloves for doing tests which was quite difficult because of the manual, you know, dexterity and when the first cases, you know, we still hadn't got a test for HIV but when the first cases of AIDS, which was clinically defined by various immunodeficiencies like thrush in your mouth or a pneumonia, if those people were presenting in the main hospital and then casualty were going AWOL as it were [laughs], it was us who were giving the advice and, you know, calming people really. And it was from the haemophilia centre that the AIDS unit began at the Royal Free because patients had to be admitted into the hospital and because they had a lung--, a chest infection there was a very good chest physician called Stewart Clarke and he joined together with the then director Peter Kernoff to get a special ward for the patients. And that was--, that was the nucleus that now is the big AIDS centre at the Royal Free. So to go back to my patients with haemophilia in this two years I was looking after them clinically but also I was doing the research. And the kind of backbone of the HIV research was because we had this population of patients who were in regular follow up and we could carefully observe them, the immunology department at the Royal Free started very early on doing what was called--, then called T4 counts but they were lymphocyte counts, and they're now called CD4 counts. And they're very--, they were the cell that went down when the HIV virus attacked. And we had these serial--, we were measuring them every time the patients came up uniquely in the world actually in this group of patients. And then towards--, the HIV virus was not identified until I think May or June of '84 and we didn't have a test until the November of '84 and we had access in a research capacity, and I mean now it's horrific what we did but it was okay at that time--, I can't even remember--, we must--, yeah, we used gloves, but we actually decanted from our stored specimens--, because we had 600 patients we didn't know who was positive and who was negative, and we decanted the stuff into little test tubes and sent them down to Richard Tedder at the Middlesex Hospital for testing and then we knew that we had 111 people who were actually infected. Now, erm, that group of patients were the backbone of a lot of epidemiological research. Now in the early days because--, they were a small cohort which was a disadvantage, but the big advantage was that there was really detailed observation on them. And we identified a lot of cofactors or things that made HIV go quickly like if you were older it was quicker, if you were young it wasn't so bad, if you had cytomegalic virus infection it was worse, if you could measure the antigen in the blood they did worse, erm, a whole load of things. And we would also present every year a progression rate in this cohort and there were two significant papers that we published one in 1991 in *The Lancet* which showed the serial fall in what then we called T4 count and we showed that if these were falling fast it was bad news you were going to get AIDS, if they were going slow it was okay. Now I mean now that's pretty obvious but at the time it was so criticised, you know, how do you know that your counts are reliable? If you take them at different times of the day are they reliable? Is the lab reliable? And all this sort of stuff. And then the second paper that was--, that really took off in the world's media, I mean we had all these interviews on the Today program and television and newspapers, god knows what. It was in the *British Medical Journal* and we showed that without treatment by projections a fifth of these patients would live for 25 years and that--, this was 1994, there wasn't--, it was the beginnings of zidovudine treatment but there really wasn't much and everybody thought that everybody with AIDS was going to kind of die. And so the insurance people were very excited about this, there was a kind of half page spread in the business section of *The Telegraph*, but also it kind of changed the view of patients and physicians and for a lot of our patients--, our patients got money from the MacFarlane Trust and a lot of the younger ones had just gone out and spent it [laughs] and it, you know, it made people rethink.

Q: Can you just say something about the MacFarlane Trust?

A: Yeah, well the MacFarlane Trust that's another interesting thing which it kind of--, I had a very personal experience about in a funny kind of way. The haemophilia community was trying to get compensation from the government and Peter Kernoff was the director and the--, I'm not sure who was leading the legal case but in 1990/1991 they were going to have a legal case about getting HIV and he was in the process of getting all the patient details together. And we were in a very strong position because we had very clear data on when they had their infusions and when they became HIV positive and why they were having the treatment and that it was necessary. And he--, Margaret Thatcher was--, was in the government and the government was standing firm and saying, "No, no compensation." And then Margaret Thatcher--, well the first thing that happened was Peter Kernoff--, no, Margaret Thatcher got turfed out and John Major came in and, you know, John--, for John Major it was very easy, it wasn't a lot of money and so he just said--, he didn't call it compensation he called it the MacFarlane--, it was called the *MacFarlane Trust after* a very eminent physician who had actually died called MacFarlane who'd practiced at Barts and Oxford. So it wasn't called compensation it was that was what it was called, but it was basically money for people in difficulty--, health difficulties with HIV. And time wise that was very helpful for me because shortly after that GRO-A GRO-A I took over the directorship. If that hadn't have happened I would have got really involved in all the depth of this legal case. So the other thing that I think--, I think the research--, I have absolutely no doubt that the research over the years from--, well really the '80s and early '90s until we had some treatment to offer the research was a safety valve for the staff actually because you really were helpless. You couldn't--, you had no specific treatment for these patients except giving them what was called prophylaxis so you put them on Septrin to stop them getting pneumonia, you put them on Acyclovir to stop them getting viral infections and Fluconazole to stop them getting thrush but you couldn't do anything else. And they were young people. It was awful. And, you know, this had been treatment that you'd given and you were seeing these patients sort of month after month and then as they got iller more closely and you couldn't do anything. So I think the research was quite helpful because you did feel that at least that was doing something. You know, it might not help this lot but it might help other people and it certainly helped us as a staff group. I mean we had a--, in haemophilia there's always been what's called a comprehensive care model where you have everybody in the team, you know, you have the physician, the nurse, the physio, the psychologist, you name it [laughs], and the laboratory and we used to have group meetings every week anyway to discuss the acute bleeding problems or people we had in for surgery whatever. So we used to discuss the clinical problems in a group and I think what that did, it certainly did it for me personally and I don't think I was the only one, it meant that you left it at work, you didn't take it home with you because it was really very depressing.

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GRO-D So, erm, where have we got to? We've--, I mean the HIV, erm, I think it would be quite interesting to talk a little bit about--, about that in general terms in London. We used to have--, this in 1983/'84, every month there was a meeting usually at the old Middlesex Hospital or sometimes it was at St Mary's, but every month, and everybody who had anything to do, any kind of involvement in this new condition went to that meeting because things were moving so fast that you couldn't really wait until it got published. It was just going really fast. And there were some extraordinary meetings. I mean I can remember when the doctor who looked after drug users in Edinburgh came and talked and he--, he had--, he'd been saving specimens because of hepatitis B I think but as soon as the test came through he had this cohort of drug users and it was emerging generally in the world about drug users but, you know, it was kind of new in Britain. When the tests first became available they had a debate from somebody from the AIDS community, a patient, and who's that lawyer who, erm--, he always advises on ethical issues? Ian Kennedy. Kennedy. And he had this debate to test or not to test because, you know; there was nothing you could do much. There was a consultant at St Mary's called Pinching who--, and Mary's were the first hospital that was beginning to get patients, and he would talk about the clinical syndrome, there were pathologists who talked about the various immunodeficiency disorders and early epidemiologists. So it was--, it was a little community. And they were young because a lot of the early doctors came out of GU medicine but there were also a few very young, very bright physicians who, you know, big names now like Brian Gazzard and Ian Weller who just got knighted, Tony Pinching, Adler. And the other thing that I suppose also began to be talked about was testing. You know, there was this big huge issue initially that you had to be counselled before you were tested. And they set up a testing unit at the Royal Free that came out of our experience and there was a lady called Reeva Miller who was our social worker who actually set up the same day testing unit, but the ethics of all that were--, was discussed at these monthly meetings. So it was quite extraordinary. I mean the other, erm, funny memory I have was in 19--, 1984 at--, was it '84? No, it was '83. The World Federation of Haemophilia meeting in Stockholm they had a lunchtime meeting to discuss this condition. It wasn't on the program it was just one hour and there was a very formidable lady called Margaret Hilgartner who looked after children in New York who was chairing it, very large lady. And Peter didn't go to the meeting and he'd suggested I took with me a slide and we'd shown that--, this is slightly complicated but people--, the patients who had factor VIII concentrate had abnormalities of their T4 count whereas the patients who had factor IX concentrate who were less common had normal counts. And I had a slide of this and I always remember that it got loaded upside down [laughs]. But what the significance of that at the time what we said was this is because the manufacturing processes are different, but it wasn't that at all it was that the people who had the factor IX concentrate, the factor IX concentrate was all made from British donors and at that point the British donor pool hadn't got a problem. So we'd made completely the wrong conclusions and that was actually--, that was published in *The Lancet* as a letter and we'd written something like 'it seems to us that it's clear that this is a manufacturing process'. But interesting when those data--, those same data were presented somewhere else there was a haemophilia doctor called Arthur Bloom working in Cardiff and he very astutely said, "Well do you think it could be something to do with the donor pool?" and he was quite right.

Q: And when did that emerge? How long after...

A: That was published, er, [pause]--, when was it? Well I suppose it actually emerged--, I mean it emerged as soon as we--, we published a paper in 1989 in the *British Journal of Haematology* that was describing our cohort of patients which was when we'd been able to test them and find the seroconversion rate and it was at that point that we realised that we hadn't got any factor IX deficiencies. And the other thing was that in our unit it had always been our practice that we treated the children with British--, NHS derived concentrate and we had no children with HIV. We acquired some from elsewhere but we ourselves had none. And so it was realised that it was from commercial product. We got fooled though as a haemophilia community because at that time in the haemophilia literature there was a lot of publication about volunteer versus commercial and everybody was measuring these T48 ratios. And in Scotland they actually had I think one donor and they had a cohort--, in the end they identified this cohort of 14 patients who had HIV but in Scotland they'd used all National Health Service--, it was plasma derived from Scotland and they thought they were okay and then suddenly they found this cohort. And that cohort of 14 patients [laughs] was studied in great, great detail because the other thing about them was that there were--, there was a control cohort who hadn't got it but had been treated with the National Health Service derived concentrate. So I suppose it--, to go back to your question when was it realised the British concentrate at that time was okay, it was probably when we got the test. I mean unfortunately, and it's something that really, really annoys me, in Newcastle they--, they had actually used concentrate earlier than we had at the Free because historically Katharine Dormandy had made cryoprecipitate at the Free and she had used that and she was quite reluctant to change to this new-fangled stuff. And it wasn't until 1978 when Peter Kernoff and the other new doctor Tuddenham--, Ted Tuddenham came they turned--, they changed everybody, but in Newcastle they'd been using the concentrates from about 1975 and so the AIDS came into Newcastle a bit earlier than we were beginning to see it. And they also--, we had a very strict policy at the Free which was largely directed by Peter Kernoff that you didn't change batches, you know, if somebody had gone on this batch of concentrate you used that batch until it was used up and the kind of idea behind that was that you would have less exposure. I mean actually when you think about it it's a bit ridiculous really 'cause you'd got 10,000 people but anyway, that was the idea about it. In Newcastle basically you took the next pot out of the cupboard whoever it was. So they were all mixed up. So they probably--, to be fair, I mean they probably did get exposed earlier than our people and they probably got a bigger viral load because they were having all this mixed up stuff from commercial stuff. And Peter Jones in Newcastle has always had this hobbyhorse that it's the dirty American blood that they collect in prisons. Now, to a certain extent that was true in that there were a lot of drug users in prisons and it might have been that you got a bigger viral load but certainly from a hepatitis point of view whether the plasma came from America, Timbuctoo or anywhere you would have got it. HIV was very, very different. I mean HIV there were very few UK experiences of HIV and in fact I think probably the Scottish one was the only one because the British blood transfusion service put in place very good rules about what we call deferrals so you couldn't give it if you'd had a previous blood transfusion, you shouldn't give it if you're gay, you shouldn't--, I can't remember there's a whole load of ones, if you'd been on holiday in Haiti probably. And I think those deferral things probably bought a bit of time, but certainly the UK--, by the time the UK donor population would have got infected one we had a test 'cause we got the test--, the blood donors I think were tested in early '85, and two the heating of the concentrates came in '85. So that was kind of lucky. And in the context of today, you know, there are one or two haemophilia patients who are really driving they want compensation and their argument is that Britain didn't get self-sufficient. Well that is an argument we didn't get self-sufficient but, on the other hand, they were--, in the period that--, well self-sufficiency would not have done anything about hepatitis. From the point of view of HIV the fractionation and the ability to provide enough was just not there and the patients were actually champing at the bit, you know, they wanted it, they wanted to have regular treatment, they wanted to be able to have their operations and that's kind of forgotten. You know, you may be able to blame America for HIV you certainly can't blame it for hepatitis and personally--, but, you know, maybe I would say that, wouldn't I? Personally I don't think that faults can be attributed and, you know, that recent inquiry in Scotland, the Archer inquiry fortunately did kind of sort of come to that conclusion but it kind of rumbles on. I mean cynically I think the patients--, the few patients driving this are probably after money actually. There was quite a big pay out--, not pay out but there is a fund, I've forgotten the name of it for a minute, for hepatitis and it's done on health grounds and also on whether you've got families and dependents. I mean the

thing about hepatitis, which of course is very different, the treatments now you can clear it. So--, and also some people did clear it naturally and now I mean there are amazing treatments. So I think that's probably most of the issues. No, one of the big issues that we haven't talked about which was quite difficult was having children. And in--, in the--, in the press and at meetings there was this story about Africa and one of the very early accounts was of lorry drivers coming down main routes in Africa and using prostitutes and there were a lot of women with--, who'd got it sexually. And we kept saying, "But, you know, none of our--, none of our patients have got it, none of our women have got it." And we did a very careful--, we encourage people to use condoms. And we did a very careful study I think there were about 15 people and we measured the viral load in the men and, erm--, and we tested both partners and the only--, the only couple that we--, well there were two couples. There was one couple who both used drugs and they'd met using drugs, he had haemophilia and he used drugs she didn't have haemophilia but she used drugs and they both had HIV and they both had hepatitis C and, you know, you don't know about that. There was another couple where she presented with an AIDS illness she actually had a kind of strange tuberculosis of her ankles and then it was realised, you know, that he'd given it to her. And we always advised--, we--, well there were several options we kind of--, we didn't advise we gave--, we explained what could be done and we tried to explain that there were risks, there was adoption and there was AID and if you really insisted then you should use a temperature chart and just have exposure at a useful time [laughs]. We had--, I'm remembering things now [laughs] I'd forgotten. We had one extraordinary terrible family, sad family not terrible family. There were two brothers who were GRO-A and they both had severe haemophilia and they both had HIV. The brother that I'm going to talk about and his wife he had an arranged marriage with an educated woman who didn't know he had HIV and didn't know he had haemophilia and she had a son, he was negative but she was positive and that family the--, what the family did was they said she was a loose woman. So she got completely pushed out of--, I think she'd been living in the brother's parents' home she got pushed out as this loose woman. She was working as a--, at GRO-A airport laying up tables for flights, you know, the meal tables, and she actually did that for a long time and then she--, she got fed up with us and went off to see some faith healer or something. I don't know what happened to her. We had patients who--, in fact I met one recently whose son is now at university, he--, they had AID but it was a--, there was a lot of--, it was a difficult discussion. And the couple I just told you about that--, where the woman presented with the tuberculosis we--, I remember we had long counselling sessions 'cause the social worker I worked with was a family therapist, we had long sessions with that couple talking about the risks of having children and in the end she actually recovered from her illness and then treatment came in and then she decided to have--, she had two children. And by then we had treatment and in the AIDS unit run by Professor Margaret Johnson at the Free they would give treatment before delivery and they've got two little children now about eight or ten, something like that. But--, so it was all quite difficult. I mean I think there is no doubt that in the haemophilia population I think sexual transmission was a lower risk and personally I, you know, I have a feeling that that's because probably anal intercourse was not probably practiced as much as in, say, the gay population. But it was an extraordinary time in that you had all these different, you know, dimensions of health care and quite really difficult emotional issues to talk about with patients. There were also--, there was one patient and his wife who got really very angry with us and said, "Well so what, I'm going to have a child," and they did very successfully [laughs] but it wasn't easy. And then the other--, the other issue although it wasn't so much my personal doctoring because I didn't--, there was a clinical assistant called Dr Goldman who used to directly look after the children but I would obviously get involved because I was director of the centre and also I had the primary responsibility for the HIV infection. But there were four--, I said we had very few children, we had four children and they'd all come from somewhere else. And one of these families they wouldn't tell the child and you had no right to tell the child but you were seeing the family, you know, and eventually this boy he was about--, I think he was about 11 or 12, it was awful, he--, they were on a visit to the grandmother's and on the doorstep he said to his mother, "I know the reason why I keep going up to the hospital, I've got HIV, haven't I?" So, you know, that was difficult.

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GRO-D So after--, I mean the unit during the--, during the 1990s it was a really exciting and rewarding time. The biggest challenge that emerged during those years was actually economic challenges. We--, because we were a very big haemophilia centre we used to have a lot of trials where we would use concentrate so that the company that was producing it would have data that it was safe, that it was good and all the rest. I mean it wasn't great science but it meant you got free concentrate. And the Royal Free became one of the first--, I think it was the second Trust hospital in 19--, well it was actually the same time as GRO-A it was April the 1st and GRO-A on April the 3rd. So we'd become a Trust and, erm, I had warned the management--, this was about 1994/5, I'd warned the management that for two years we'd have virtually all our concentrate from--, free. And I said, "This is coming to an end and, you know, it's big money." It's sort of--, at that time it was about a million pounds or something. I said, "You've got to get this in your budgets," and at that time, you know, there was all this business that you--, they even had fundholding GPs, didn't they? So the haemophilia centre had this really expensive service that they had to put contracts in place and they really hadn't got a clue. I mean it's not really their fault because this was a new system of purchaser provider and the Trust having its own budget and they, you know, haemophilia suddenly had put them all in the red and the extraordinary thing that happened was it was all tipped on my head. And I was told I wasn't--, I wasn't budgeting properly and I said, "Well hang on a minute," you know, the way the Royal Free manages, which it did then I guess it still does, doctors doctored and managers managed. I didn't have anything to do with contracting. And then it became particularly difficult because--, because of all the HIV and the hepatitis there was a tremendous push to get everybody on to recombinant products and the recombinant products were in trial. I mean we had the first patient in Europe in the recombinant trial in 1988 and I think they got licenced in 1992 and we still weren't allowed to use them in the UK, and then in 1995/6 we started producing guidelines in the UK. There's a very strong Haemophilia Centre Directors' Organisation in the UK and they presented--, they got guidelines together that said that we should be using recombinant product and we were pushing this to our managers and they weren't having any of it. And our children started going down to Great Ormond Street where they were having recombinant. And the whole thing came to a crunch when we had a very articulate mother, I think she was a psychologist or something, but she was very articulate, very nice woman and her son who he had not severe haemophilia it was moderate haemophilia so he didn't need regular treatment all the time but he needed treatment if he had an operation. And he was going to have a grommet operation and she wanted that child to have recombinant and we wanted him to have recombinant but, you know, our managers weren't budging. And I--, she said, "What do you want me to do about it?" I said, "I don't care what you do about it." And I had given--, because she was, you know, putting pressure on me I actually gave her a copy of a letter I'd sent to the chief executive arguing the case and saying, you know, 'with all this history of transfusion transmitted disease we should at least be treating our children with recombinant and it's UK guidelines' blah, blah, blah, blah, blah. So I gave her this letter and she knew a journalist on *The Independent*. And this sounds like something out of a novel, I had gone to Tehran to give a lecture on blood, the risks of blood transfusion [laughs], I'm in my hotel room in Tehran, Roy phones me up and he says, "You've done it now [laughs]." And there was this double page spread in *The Independent*. You know, *The Independent* used to have a kind of nice magaziny thing where this--, a picture of this mother and her child and the journalist, her friend, had written this double page spread that had all the--, it was very accurate, it was you couldn't fault what she'd written, but she'd taken big extracts from this letter I'd sent to the chief executive. And to be fair to him I mean immediately when I got back I thought I was going to be in the soup but actually he was--, I mean he was quite reasonable, I suppose

maybe he realised that they were offside I don't know, but they changed--, the children were allowed to have it. The adults didn't actually get recombinant I think until 2002. So that was quite exciting [laughs] but it was also ironic that here you are lecturing Iranians about HIV and hepatitis and back at the ranch [laughs]...

Q: How did your colleagues respond to that?

A: I don't--, which colleagues? The colleagues at the hospital I think they were behind me. I mean one of the things that I did and it was partly for my own survival it's probably partly because it's the way I am, I was always very open. So I used to--, we used to have a weekly meeting discussing the forthcoming week because the patients who were coming up and needed blood tests we had to make sure the laboratory hadn't got too many of them, we might have people coming in for surgery we needed to make sure that people knew about that and we, you know, are going to be ready for this and the physio and all the rest. And I used to use that kind of meeting to let them know what was happening and certainly with the economic issue I mean I had--, I got a grant and employed an economist to do a PhD and so all that work was shared in the unit at presentations and things. So they knew what was going on and I think they were supportive. I mean the--, the research guy I got he went on to--, he's a lecturer or senior lecturer at London School of Tropical Medicine but he did a lot of work on quality of life. And, you know, the other big financial issue that was emerging was the children, we began to treat the children with what's called prophylaxis where you give them three injections a week to stop them having bleeds rather than treating them when they had bleeds and of course that costs much more money. And he did a lot of work on showing that, you know, in the end the quality of life is better and actually in the end you avoid surgery and all sorts of stuff. So I suppose we, you know, in those years we kind of mixed up the service element with clinical research really and that was always shared in the unit. The other thing that I was a great believer in, I really wanted people to, you know, haemophilia is very rare and we had a very large number of patients and it behoves you to do research to progress the management of the disorder. So I was very keen that we always had a presence at the main meetings and that people presented posters and that they then went on to write up whatever they presented as papers. And we always had a tradition in the unit that once a week we had an hour where we sometimes had visiting lecturers but mostly it was people within the unit presenting their stuff and I think--, I think it was very good because I think it was educative clearly but I think people also felt proud. I mean certainly they felt proud when they went to meetings 'cause, you know, people thought very highly of the Royal Free. And I think it, you know, they probably were better actually. And the--, I used to--, we had--, I didn't--, I did some private work but all the private money went into the department because actually the essence of doing bleeding tests, complicated bleeding tests, the lab are doing it, you know, you're not, all you're doing is interpreting. And so we had a common fund where private monies went and a large amount of the private monies were prothrombin times which was a measure of bleeding and because in the hospital they had a big liver unit and they had a big renal unit and a big cardiac presence all those--, a lot of those private patients that had that care had prothrombin times some of them, you know, daily and all that money went into our private fund and we used that for travelling to meetings. And what I used to do was I--, this was in, you know, the days before you did everything online, there was a travel agent across the road on Haverstock Hill and I used to book passage--, package holidays. That was the cheapest way of getting people to meetings if you--, if you booked, you know, supposing you were going, I don't know, Bangkok or Washington or wherever it was, if you booked a cheap package holiday you got the air flight, you got the hotel, it's all done and that's what we used to do. And, you know, sometimes the world haemophilia meetings maybe 10 or 11 people would go. And the other thing I used to do is I used to make them all give some kind of presentation when they came back so--, because I thought it was very important that the people that were behind didn't think we'd all been off on a jolly. I mean, you know, part of it was a jolly but there was also networking and work that went on. GRO-D

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