

Alan Emery



'A recent photograph taken during a talk on 'Art and Medicine' – aptly with a painting of Laënnec with his stethoscope in the background' - Alan Emery 2010

Personal Details

Name	Alan EH Emery
Dates	Born 21/08/1928
Place of Birth	Manchester
Main work places	Manchester, Edinburgh
Principal field of work	Medical genetics
Short biography	See below

Interview

Recorded interview made	Yes
Interviewer	Peter Harper
Date of Interview	10/08/2005
Edited transcript available	See below

Personal Scientific Records

Significant Record set exists
Records catalogued
Permanent place of archive
Summary of archive

Biography

Alan E H Emery was born in Manchester and after military service, studied at Manchester University, gaining a BSc (First Class Hons) and subsequently MB ChB (First Class Hons). In 1964 he was awarded PhD in Medical Genetics at Johns Hopkins University, and returned to Manchester to set up a Medical Genetics Clinic, the first in the UK outside London. In 1968 he was appointed Professor of Human Genetics in Edinburgh. In 1989 he set up the European Neuromuscular Centre and was its first Research Director. In 2001 he established the Section of Medical Genetics at the Royal Society of Medicine, becoming its first President.

In his long career he has published some 400 papers and written or edited over 20 books, mainly concerned with human genetics and neuromuscular disorders.

He continues to be actively involved in writing and lecturing on neuromuscular disorders, as well as his hobbies of painting (portraits and landscapes); he is a published poet.

INTERVIEW WITH PROFESSOR ALAN EMERY, 10th AUGUST, 2005

PSH. This is an interview with Professor Alan Emery on Wednesday 10th August 2005 at his home in Budleigh Salterton in Devon

AE. I suppose my career started in an odd way because when I left school during the war I had no ambition whatsoever and left with a terrible school certificate and then worked in a dye factory. Then when I was in the Army and coming up to demob, the colonel was a very good chap and he said 'What are you going to do when you leave the Army Emery?' "I don't know sir." 'Well you can't go back to work in Geigy Chemical Company as a manual labourer in the factory.' I said 'no I can't'. He said 'why don't you go to university?' I didn't know anybody who had been to university. Nobody in our family. So I thought this was quite incredible. Anyway I did get the results and I did go to the University and I went to Manchester because I had grown up outside Manchester and I hadn't been back for nearly 4 years by then. So I went there and studied botany and zoology and then did some research but I really wasn't happy about it. I don't know why and I came down to Devon and I lived in Woodbury Salterton and I got a job teaching at Hele's School in Exeter and every night we played chess, the GP and I, and he said if you want to do something why don't you do medicine, and I thought this was like walking on water to me at the time. He said 'of course you can.'

He came from Glasgow. He was a very nice chap and they sent him down here because he had TB and they thought this would help, the fresh air, and so I eventually plucked up courage and applied. Nobody wanted me of course, no medical school, because by then I was quite elderly. I was 29 and eventually Manchester again accepted me on the condition that I did alright. Well I got through medicine OK but it was very difficult at that age, qualifying at the age of 34. And of course there were very few career options open and I remembered what one of the chaps in the Army had said when we were being demobbed, 'choose a subject where there is not much competition' and that seemed true in genetics then and I think I was encouraged by Lord Platt who was then Professor of Medicine and was a delightful man and he encouraged me an awful lot. And then he said one day 'Would I like to go to Hopkins?'

PSH Might I stop you there a moment Alan, because we are going to come on to that with quite a lot of detail and before we go on to Hopkins can I just ask, where were you actually born? What part of the country? Was it in the Manchester area?

AE. Well it is now, but it wasn't then. It was a place called Gorton, which has been famous recently because of that chap who killed all his patients, but east of Manchester towards the Pennines. But we came from a very poor area, I tried to show one of my daughters where I lived but it's all been pulled down. It was two up and two down, stone floor downstairs and an outside toilet, a midden, and gas light, no electricity of course and a very poor background indeed. And this is perhaps a factor, but you don't want all the psychological things, but I have never ever been ambitious. I think I have always been looking for a quiet life, which David Brock, my colleague, used to think was

terrible because I should have been more ambitious and pushy and I didn't. It's the nature of me. I'm just not like that.

PSH. So among your family was there anybody at all who had an interest in science, medicine anything of that type?

AE. No, not at all. My father was a postman and my mother had been a mill worker. There was nobody in the family at all, nobody.

PSH. And the Army, were you in that for national service after the war?

AE. It was the very end of call-up and I was a conscientious objector. I was a very strong Christian in those days and I still am a pacifist, but eventually I went in the Education Corps attached to the Cavalry regiment and I found it was the blind leading the blind because I knew less than some of the other people, but it was because I didn't want to be in combat.

PSH. So that gave you a bit of an opportunity in the teaching direction.

AE. It did, exactly, and I think that's why the colonel encouraged me to go to the university.

PSH. Do you think that is something that has persisted in the sense that you have always enjoyed teaching?

AE. Very much. I think that's true. I enjoy teaching very much. Teaching medical students on the ward, with beds, outpatients yes. I have always seen this relationship with patients, and students of course. In fact I would say if I am very, very honest, when genetics turned more and more to laboratory work I became a little bit disenchanted. And I remember having a meeting at the Royal College of Physicians when Cyril Clarke was President and we were trying to draw up criteria for medical genetics and he embarrassed me terribly by saying 'well you don't need to take all these higher qualifications. All you need to do is get your MRCP and read Alan's book' ['Elements of Medical Genetics']. He was a proper physician, interested in genetics and I had a tremendous respect for him and the same with Robert Platt, although Platt was nowhere near as good a geneticist of course. So I think it was the clinical side more than, - in fact the very first paper I ever wrote, I could have called 'Lyonisation in Duchenne Muscular Dystrophy', instead I called it Clinical Manifestations because I wanted to get my hook into the clinical work.

PSH. Coming back just to the Manchester medical school, you went into medicine to get medically qualified. Did you have any idea at that time or going through that there was any special type of medicine?

AE. Yes I had a very strong feeling about this. Going to medical school in 1955 or '56 my ambition was to get one of these country practices either down here in the south west or up in the north west highlands. My mother was Scottish family, actually Marcia's family is Scottish, and you got what was called an inducement pay of £1,800 a year. They were called dispensing practices. You did your own dispensary and had somebody to help you, and I imagined that would have been my life and would never have retired, but you

see later medicine changed and we started having these group practices, became more technical and I got swept along with this. But my ambition was to be that sort of doctor. They still exist but not in Britain. In New Zealand they do for instance. I spent some time with a New Zealand doctor a couple of years ago. It is still like that, you can still do it on your own. Have your own practice in the country. That's what I would have loved. I can imagine fishing by a river or a loch and a wee old biddy running down and saying "doctor she's just about to deliver" and me going up to the village and doing it. And that would have been my life until I died. I would never have retired. And that's what I really wanted to do but it's changed. Medicine is not like that now.

PSH. You mentioned that Robert Platt encouraged you in the direction of genetics.

AE. Yes he did.

PSH. Now was that when you were a student or after you qualified?

AE. Yes. When I was a student, he dug out, he must have gone through the qualifications and he realised I was much older and I had already got a degree and so I think that might have been, since it was in biological sciences and he used to hold meetings to which I think Polani once gave a talk and Malcolm did, Malcolm Ferguson-Smith. And he used to hold these meetings in the evening for consultants, and he used to ask me if I would show the slides, so I used to go about once a month to this evening meeting and show the slides and I saw what was going on and showed an interest and of course then genetics was terribly exciting because it was all to do with clinical work and sorting diseases out and that seemed very exciting to do that. Especially since I kept seeing patients on the ward, because then I was a proper doctor, that I could sort out.

PSH. Just remind me what year are we at now, roughly?

AE. I qualified in 1960.

PSH. So the human chromosome number and the first chromosome abnormalities had just come on to the scene?

AE. That's right.

PSH. I always think of Robert Platt in relation to blood pressure and 'Pickering and Platt'. Did he have wider interests in genetics and medicine?

AE. Well yes. He wrote a book about his life and he mentions this in his life. I think it's called 'Private and Confidential'. He was a very honest man. I think that's why I liked him enormously, warts and all, you got to know everything. There is a picture of him there. And he was interested in this, yes as you quite rightly say 'Pickering and Platt'. Pickering thought in our terms now as multifactorial and Robert thought it was unifactorial and had two peaks and so on. He really went on and on and on about that. He had an interest in genetics but apart from that I don't think he was very knowledgeable about

this. But then it was only just developing. None of my teachers at medical school had any idea and when the DNA came out in 1953 I didn't understand a word of it. We read it in the newspaper, we didn't read Nature in those days, not people like me anyway, and it was in the Times colour supplement at the weekend and I couldn't understand it. We still were taught that protein was the genetic material. I even had two professors when I was doing science, both Fellows of the Royal Society, both very eminent, a chap called Wood Jones and a chap called Graham Cannon who taught that genetics was really not important at all and they actually believed in Lamarckism. I have got both their books. Quite incredible. That was in the late forties.

PSH. Was that the anatomist Frederick Wood Jones?

AE. Yes Wood Jones the anatomist and Graham Cannon was a zoologist and both had no respect for genetics at all. I could go into this in more detail, but I mean they didn't. So you were taught really by people who had no interest in genetics and when I got to medical school they were the same. There was really no interest among the consultants in genetics. Not at all. None of the teachers, except maybe Robert Platt, but he was teaching mainly renal disease so I don't remember getting notes on genetics at all in the lectures. And then Douglas Black took over and he was a little bit more interested in genetics but there was nobody really power driving, so that was the situation as a student.

PSH. How then did the link with Victor McKusick come about?

AE. Well I think McKusick used to write to people, when he got money from the public health department, for Fellowships and he must have written to lots of people and he wrote to Robert Platt and Robert Platt put me up for this Fellowship to go to Johns Hopkins and for reasons I will never understand I got it and went, which was quite a thing in 1961 because I had only done my house jobs and I really didn't know much about medicine. Though I had done very well in my medical exams and so on, top of the class and that business. It was quite astounding because when I first got there McKusick was still a cardiologist and he was just beginning to get interested in genetics and he pushed me towards a chap called Ned Boyer in the laboratory. Ned said, well your project now will be to work on bumble bees and I thought, I haven't given up a career, my whole life, you know I had to sell my house to do medicine. I had given up everything to do that. I wasn't going to go back in a laboratory again. That wasn't my idea at all and so I registered for a PhD which I wasn't supposed to do. You know, you have so many hours of class work to do to get onto the programme and they didn't count many of the exams I'd got in Britain as important or necessary, but I swallowed my pride and did things in biochemistry and so on and so on. And at the end of the first year I got the necessary credits and then went on. Then I looked for a project and by chance Victor, who was very interested in linkage and I certainly wasn't, I was still a clinician, and he gave me a paper that was to do with linkage in Duchenne and that got me interested in Duchenne and I followed up one or two families, but I couldn't get excited about linkage. It was to do with G6PD in those days, Xg and colour blindness, and most families I looked at weren't informative, so it was a bit depressing. You know it was a long time ago, it's not like that now of course, but it was then. Then I started collecting all these

families and the neurology department at Hopkins then was run by a Canadian called McGladdery, a very nice man who let me do what I liked but he had no academic interest whatsoever. And so I just collected all the patients I could from all over Maryland and I went all over the place and I went over to see Hideo Sugita who was working in Salt Lake City with Tyler and Sugita had got this CPK test from his boss Ebashi but it didn't work very well and I fiddled about with it and got it to work much better when I got back to Hopkins. Now of course there was a trick in this and I think I was very, very fortunate; because I have got an obsessional personality, if I collected blood from patients I would measure it straight away, no matter what time I got back to the lab, I would do it straight away and I got remarkably good results and when they were compared with some other people they had results nothing like mine. Then somebody at a meeting said 'Do you add cysteine to your reaction to prevent the CPK degrading when you store it?' Well I didn't. I didn't store it. So I had CPK and added cysteine to it and got the mixture going and that's the mixture actually that was taken over by Boehringer (?).

PSH. So really by the end of your first year or so you had probably got a large number of Duchenne families.

AE. Yes

PSH. And at that point were these Duchenne and Becker, or mixed in?

AE. Yes they were, jumbled up and I always remember one family if you are interested. I used to have hair in those days and I went to get my hair cut just by Johns Hopkins at Monument Street at the barbers and I noticed the barber wobbled when he was going around me. He was in his twenties and I said, what's wrong with you? and he said 'I've got muscular dystrophy. I've got Duchenne'. And I thought you can't have, you are in your twenties; and so then I started talking to him and it turned out to be my introduction to Becker muscular dystrophy, he had a big family and which of course in those days John Walton didn't think existed but I was pretty convinced about it, and then of course as you know, because you've got the details, another family I fell over was the Emery Dreifuss, because that was a big family with Duchenne and I realised that couldn't be Duchenne; then when I saw them I realised it wasn't Becker either. So that was another one and that really was what I enjoyed, examining the patients, seeing and talking to them and as I said in that little article, which incidentally I was asked to do, I would never have done it otherwise. It was nice to do it in those days. Because you could do everything yourself. You could examine patients, you could do biochemical tests and it was really very, very exciting, so that's how it started.

PSH. Am I right you wrote, I really enjoyed that article on the Emery Dreifuss family.

AE. (Laughs)

PSH. No I really did. And am I right the family was up in wildest Appalachia?

AE. Well they were up in Virginia, Tennessee, that whole area which was really lovely and very isolated and they were a delightful family. I have seen

them since of course, 25 years later and the funny thing is the proband was a teacher of French/English extraction; he died some years ago and his wife when I saw the family 25 years later in 1987, when I got off the bus she said "Oh you have put on weight". I must have been incredibly thin. But the family were delightful and when I think back to these studies, these early studies, I think that's when I got most excitement out of genetics when I was doing it. Perhaps with a field worker, perhaps with my wife then. She used to help me a lot. I was really excited about it. The excitement sort of went a bit as years went by because we became far and away more technical and we were always sending blood off to get tests done for things. You were no longer in charge of what you were doing. But those early days were tremendously exciting. I loved it.

PSH. Do you think the fact that one had to go to the family's home to sort things out was a factor in that interest?

AE. Very important. I'll tell you why. The very first family I saw with Duchenne in Baltimore were two families. I picked the notes up and McGladdery said take those Alan and start with those; you see I had very little to do with Victor by the way except going to his seminars whenever it was, because he wasn't interested in this field at all. He encouraged me but he wasn't interested, so I took these off and the first family I saw lived, oh gosh I can't remember now, it doesn't matter where now, just outside Baltimore, they had a swimming pool and they had these two boys, one was about 10 and the other about 8, both hobbling around. Had a swimming pool, a lovely house and the children, though they couldn't really walk well could swim and Dad was pushing them about in the pool. They were very, very wealthy. In fact there was a famous film star Hedy Lamarr lived in the same road. Well that was my first family I saw, perhaps in the morning, and then in the afternoon I went to see a coloured family in downtown Baltimore up about 4 or 5 flights of stairs and saw this boy who was the same age. It still upsets me. He was in a wheelchair and he never went out. And that's when I began to realise you know, the social and environmental background was so very, very important in dealing with these children, quite apart from the science. Do you know what I mean?

PSH. I do indeed.

AE. And this poor kid, his mother and father had just left him there, you know put by the table what he wanted to eat and the television and that was it. That was his life. And I couldn't believe it. And of course as time went on I saw many, many more cases like that in Lancashire, in Yorkshire and in Scotland of course.

PSH. Alan, you mentioned that your work didn't really give you a lot of contact with Victor

AE. Well it did.

PSH. but did you go to the Thursday lunch-time clinics and all of that?

AE. Oh yes, sure. Of course. Well

PSH. Or maybe they hadn't got going?

AE. Oh they had. He started doing clinics about the second year I was there, but it was difficult for people like Roswell Eldridge and myself who weren't interested in these dwarves he was collecting from the Amish country. I went to the Amish. I collected family trees for him but I was just doing it as a sort of "dogsbody". I wasn't professionally interested in it. I felt in a way like Roswell that we were just perhaps helping him to get these families together. It wasn't my field and I did say in that article when I gave my seminar after seeing this family with EDMD which turned out to be unique, there was absolutely no interest in it at all. Most of the stimulus I got was from a chap called Tony Murphy and Tony was an odd chap, but very, very helpful to me and when I gave a seminar right towards the end when I had finished my PhD and I was really talking about how we'd used Bayesian statistics which he taught me by the way. He taught me how to use Bayesian statistics. Nobody had used Bayesian statistics before. I don't know how he got hold of it but he did. He was a mathematician and how to do all that business and I got a bit hammered from the members of the seminar group and Tony was very supportive and said 'well this is where it's going. You may not like it but that's the way we are going to have to do genetic counselling. We are having to take into account all the information, the family tree, the enzymes'. So Tony was good. But Victor was good with me, don't misunderstand me and he was very encouraging. He offered me a job too at the end, as an instructor in medicine. I was very tempted because I loved working, I loved America but I had not seen my parents, they'd never come to America and I felt I ought to go. Then Robert Platt offered me a lectureship, so I had this decision to make. And the nice thing about the lectureship was, it was in medicine, not in genetics, so I still had beds and I could still look after patients and I'd got my membership by then anyway, and so that meant that I could be what I used to call a proper doctor, but with an interest in genetics and I started a clinic and that's all in there, how it started. That was 1964.

PSH. So am I right that that lectureship was a completely new post. There wasn't anybody who was in the field of genetics in Manchester?

AE. No, I don't know about that Peter. No, but it wasn't a lecturer in genetics, it was a lecturer in medicine.

PSH. With an interest . . .

AE. With an interest in. And you know Dian Donnai, she gave a talk at Green College a few weeks ago, a very good talk indeed and actually her first slides were of my first pay packet in . . . I don't know how she found it, about me and I got I don't know, some ridiculous salary then. She was intrigued because they know in Manchester it all started in Manchester, outside London. It really started there I think. Not me, Rodney and the others. I suppose I should take credit having started it because I started a clinic there. I remember one of the very first cases I saw was interesting. It was an Irish lady, Catholic so she didn't use contraceptives. Terribly nice woman. Lived around the corner from the hospital. She had two children with spina bifida and there had been some research in rats showing if they gave them, I think it

was mercaptopurin but I could be wrong. Something for the prevention of metabolising folic acid, they got offspring with spina bifida. So I gave her loads of folic acid but she still had a third child with spina bifida. So we took her off folic acid and measured her folic acid levels during pregnancy. I didn't, haematology did, and she had her fourth child with it and I remember writing this up because Mike Laurence always thought it was important because we now know that folic acid prevents spina bifida but there may have been other factors. I have not kept up with the field. But that was one of the very, very first patients I ever saw with spina bifida.

PSH. So would I be right that when you started in Manchester you were on your own without anybody to help you?

AE. Nobody there, no.

PSH. So how did things evolve in Manchester?

AE. Well, I got a secretary and I got a technician who was a fireman. He wasn't properly trained but he was Alan Knowles. He was so nice you know. He was very interested in iso-enzymes. That was the big thing in those days and we were doing LDH iso-enzymes in muscle and things like this and then I got some money from the University, a university grant to get a lecturer to do cytogenetics and I got a chap called John Timpson, who is now something to do with the Eugenics Society and it was really the two of us trying to do it but of course to do the cyto, we started the cytogenetics service but John was really in competition with haematology, and they had a very good cytogenetics service, not for children with Down's syndrome and so on, but for leukaemias and things like that. So when I left in '67 to go to Edinburgh, I suppose then the writing was on the wall. It needed far more input and that's what Rodney did. When I went back a year or two later Rodney showed me he'd got new staff, a new laboratory, it needed that. I told you at the beginning I was never ambitious. I'm a pretty lazy guy and I don't push things and I should have done. I realise that now. But I was enjoying it and John was a nice guy to work with. He may not have been the best but he was a nice guy to work with and very supportive and we got all the students behind us and we used to have Sunday morning meetings at the Royal Infirmary and the students used to come on a Sunday morning because genetics then was new. And of course I had been so encouraged at Johns Hopkins because of meeting all these famous geneticists, and in Britain there weren't many. I don't know if you want me to go on with that just at this point?

PSH. Well I'll come back to that but I would like to ask you, was this the point where you first wrote your book, your Introduction.

AE. The Elements?

PSH. The Elements.

AE. That was written when I was in Manchester; I had come back from the USA but it was written for the University of California Press and they did quite a good job, but no proper illustrations. And that must have been about '66. Then when I got to Edinburgh, of course we had all been brought up on E and

S Livingstone's textbooks of medicine and God knows what. They were the big medical publishers when I was younger and I went to see them and a very nice chap who ran it, can you imagine one guy, a retired teacher running a publishing house. You can't imagine it now. But he did and he said 'We'd love to do this Alan. We've got to bring it down to less than one pound. Nineteen and sixpence and we will sell it.' So that's what we did and they bought the rights from the University of California who really weren't interested in it and we got the Elements off. That's how I started. It's now done by other people. It's not done by me.

PSH. So you were back in Manchester for four years was it?

AE. Nearly anyway, yes.

PSH. How did it happen then that you moved to Edinburgh?

AE. Oh it's a long story, but essentially I got promoted. I was offered a chair in Newcastle and I didn't really want to go. No, a readership in Newcastle and I didn't really want to go to Newcastle. Robert Platt therefore got the University to promote me to reader to keep me there. And I was, I mean my kids were now going to non-fee-paying schools, very nice ones. We lived in Bramhall and they were nice schools and we were very, very happy there and I'd got John and a secretary and my technician and one or two other people. However, there were two readers in medicine. There was Geoffrey Berlyne, who was very powerful, very, very famous for renal disease and myself. My readership was as a reader in medicine, so beds and the usual thing that go along with being a consultant but an interest in genetics. One day he came in, Geoff, I think he didn't want any more competition, I don't know and he flung the Lancet on the table and he said "Alan why don't you apply for this?". I thought, I won't get that job, Good Lord! "Why don't you try?" So I had a word with Robert Platt and he had then left. He was in London as the President of the RCP. He said "Well yes, do apply, I'll give you a reference and Douglas will". So I wrote to McKusick, he said he would, so I did. But I was with big competition there you know. There was Jim Renwick, John Edwards, David Harnden, all internationally famous. I was not known. But that may be the reason why they appointed me because they thought I won't be in competition with anybody who is in-situ because Edinburgh in those days, I don't know if it's changed much, there were a lot of people in little areas I know were very defensive of them and it was extremely difficult to get the thing going, and I seemed to be thwarted in every step of the way. And the other thing, I made a very, very big mistake. I took the University on its honesty and I will just tell you a little anecdote. For the first six months when I had been appointed in '67 I was going backwards and forwards because I still had clinics in Manchester and they couldn't get someone to replace me, so every week or so or two weeks I would drive down to Manchester. No motorway then. It used to take me the whole flaming day and the secretary there would arrange all these patients and I would see them. But the very last was just before Christmas and I told Douglas, I can't come back again because January 1st 1968 I just have to start in Edinburgh. I had been doing the odd thing in Edinburgh but that was it and so, there was a cocktail party. I didn't drink in those days and I wasn't a great one in cocktail parties anyway. I went there and the Dean said to me, and I don't mind this being recorded because it is all

on the record and he said "Well you will be glad to be coming to Scotland won't you Alan?" I said "Yes my mother's family were Scottish. Yes it will be nice really. That's why all my children have Scottish names you see". And he said "You will love it". I said "Of course I am coming here really because I have all this chance of having a lectureship to do this and a lectureship to do that." This was a department not a division so it had equal status in the University with Surgery, Medicine, Dermatology. The big departments. Orthopaedics. You see. And so it wouldn't reflect my research interest, that would just be me. The others would have to do their own thing. "Oh" he said, "You misunderstood. I mean you won't get that now". Well I froze, and my wife and I went home and she said "what's the matter?" and I was deeply upset and so she said "I think you'd better go back to Manchester and say you want your job back." So I went to see somebody and they said go and see the Vice Chancellor. So I went to see the Vice Chancellor and he said "You know you are in for a chair here" and I thought oh God why didn't they tell me. It was a personal chair, not a department, just a personal chair in medicine. And he said "Douglas Black is such an honest chap he wouldn't tell you until it had gone through but it was pretty certain." So I thought well hang this. So I went back to Edinburgh and I went to see the Dean. Are you interested in this?

PSH. I am yes.

AE. And he said "well you know a bit about it now". I said "Well I've decided to resign the chair". Now nobody has ever done that in Edinburgh. I didn't know that then and he said you have to see the Vice Chancellor about this and so I had to wait outside his room like a little schoolboy. Then he came out in about half an hour and he said "The Vice Chancellor" who was Lord Swann "will see you at 2 o'clock." So I went in to see him totally convinced we were going to go back and he said "Ah my dear Emery, now what is it you wanted?". Now I got everything I wanted, but it made me very, very unpopular from day one because the lectureship I got for David Brock was taken from surgery. I didn't know this at the time. The lectureship for another consultant, which you remember about, was hotly contested because they wanted a consultant from Edinburgh. Remember that? I do. And I was deeply hurt about that. I never told you about that but it doesn't matter now, and so on. So right at the beginning it was difficult. The second phase that made it difficult there was, they had a Horizon programme where I figured prominently. I had only been there ten minutes, so that lost me points and I think probably the third thing that did it was the MRC came, or the UGC, to look at all the departments in medicine and to classify them from nought to five and I don't remember who the secretary was now. Perhaps it was Himsworth. I can't remember. And all the professors came in and there were about 30 in the faculty of Medicine in Edinburgh, full Professors, not associates. The proper ones. Heads of Departments, and he went through all the departments of course and said "Surgery you get five points Sir John Bruce", because the big departments were good there, they were excellent, they really were and then right at the end, they hadn't mentioned me of course. I was an 'also-ran'. I was right at the back. "There's one department we really do want to encourage and that's human genetics". So those three things . . . So right from the first year it was incredibly difficult and I made this terrible mistake of trying to do a department when what I should have done is

what people do now, a research unit like Kay has done in Oxford. The whole department revolves around her interests. She has no competitors, nobody in her unit saying I want to do this, I want to do that. They all worked in a similar area and I think if I had started that way I would have got the confidence, but I didn't, I started right off with people who want to do their own thing and that wasn't such a good idea. Probably it was for genetics because they were very good in their own ways. I mean David discovered the alpha-fetoprotein, Charles Smith developed all the stuff for the computerised registers. Molly did a lot on dysmorphology and developed new syndromes but it meant it was a very disparate unit. It was supposed to be a department but it became difficult to manipulate and get grants. Do you understand?

PSH. I do. Tell me a little bit, actually particularly about Charles Smith and David Brock, because of your colleagues in your department there, they are two who made outstanding contributions.

AE. Yes they did and I have great respect for both, but you see they were two big fish in a small pond. That was the trouble. Charlie eventually headed up a department in America. Don't know if you know that.

PSH. Yes.

AE. In computing and so on and he became very famous in his own field. And that's where he was.

PSH. Didn't he have an agricultural background?

AE. Yes he did. In Aberdeen I think.

PSH. Because he was one of the first to start, I suppose, almost like Tony Murphy, to start applying those mathematical approaches to . . .

AE. He did. To linkage and things like that yes. He did and to ascertainment and all that business that really we don't bother with now. Segregation analysis, but I mean it was a big thing then.

PSH. Well it was the foundation.

AE. Of course. Absolutely. But I think he felt that he was a senior person and he wanted a chair himself. Now David was very similar and David was a very, very difficult person to get on with and he never had staff work with him very long. I don't know if you know that but I respected him enormously because he was very good and very hard working. And he was very sad when I went. He came to my farewell and gave a very nice speech and I was very touched. He did say some nice things like, we didn't always see eye-to-eye but we always respected each other, which was absolutely true and that I didn't mind. I didn't mind at all. But you see he was working eventually on CF. He had a big grant for that. You know the department becomes very disparate then but I lived with it. But then remember, I think it was 1983 that Margaret Thatcher said she wanted to get rid of dead wood in the Universities so I volunteered for premature retirement which was the best thing I ever did because I don't think, how long had I been there then. Fifteen, sixteen years,

a long time. Douglas Black used to say you should never do anything more than 10 years. I think there's some truth in that because you become blasé. Anyway, whatever. I decided to take premature retirement.

I got a Royal Society Research Fellowship and a Wellcome thing and all sorts of things which allowed me to go on doing research which I did for 2 or 3 years but really that meant going back to lab work and we lost our way a bit. I remember Ed Southern was my guiding angel in those days, and we cloned the wrong end of the X chromosome. Well you know, these are the sort of things that happened in those days but it was very exciting and as head of a department and not a unit, you had an enormous amount of responsibility. I had beds. I had 6 adult beds, access to paediatric beds as well. Outpatient department, clinical teaching, formal teaching, administration and on endless committees the university expect me to be on. I was chairman of the discipline committee for seven years, which was an enormous job, for the whole university. To be honest you see, when I talk about this now to my colleagues who work in genetics, they don't get involved like that. They are not expected to for a start and if they do want to get involved they usually volunteer for it. Well it wasn't like that, we were expected to do it. Postgraduate study committee, travel and research, the library, discipline, those four major committees and the discipline committee took an enormous amount of effort and work and a big committee. I think there were three or four divines. You know that was a lot of work.

PSH. Do you think that was particularly a problematic area in Edinburgh?

AE. I don't know. They were funny about some things. I don't know. Perhaps I wouldn't want to record this because I suppose those cases were confidential.

PSH. Sure.

AE. But there one or two that were to do with sex or to do with somebody having an affair with somebody else in the department, something like that. But there were all sorts of other things. If it was a criminal offence that was totally different. That went to the police. These were things in between. I'll tell you one story which I love telling. There was a young man, you see a letter used to come to me, we had a permanent secretary, a man in Old College. It says "Dear Professor Emery, we have this" if it was something that couldn't be done by the head of his department, the Dean of the Faculty came to us. This was a boy in his final physics exam, was found cheating. He had got a piece of paper. This is considered almost criminal in Edinburgh you see, and so I said we had better convene a meeting. When is convenient. I said how about so and so, and the secretary convenes the meeting. I don't know whether you remember that painting "When did you last see your father?" It always seemed a wee bit like that. The chap would sit there you see and this table with all of us sitting there. First of all he would be outside and we would discuss it and then decide we'd call him in. He must be rusticated, he must be sent down. This is terrible. He comes in. He is totally not the image we expected. He didn't have long hair and a beard. He was neatly dressed with a sports coat. He came from the Outer Hebrides and nobody in his village had ever been to university. He spoke with this

wonderful highland accent and that broke us up. So the professor of divinity said [*whispers*] 'I think you should decide this.' So I said "This is a serious offence. "Oh I know that sir". I said "you must go home for a year. You can tell your parents anything you like and come back next year and you have to take your exams again". So it rounded it off. It was a very nice job to do, I enjoyed it, but it was a lot of work and you see that on top of everything else. And then the problem to try and run a department, more and more we had to raise money, but don't get the wrong impression. David was very supportive when he got the money in the department and he was excellent at teaching and we had an honours BSc plus – oh I never mentioned those - an MSc, both the first in Britain I think, an MSc course, a number of DPhil students and MDs. There was a lot of teaching there as well but he was very supportive and we never had an open row, it was just that I always felt he should have got a better job but I don't know why he never did.

PSH. What about the MRC, that can't have been easy having to share the building and everything.

AE. That was difficult at the beginning. That's right. It wasn't like that when I went there. We had our own separate little units which was a series of portakabins and then they built this new MRC unit which was really for Court-Brown who was very famous because he done all this on leukaemia and the effects of radiation and worked with Richard Doll as you know.

PSH. Court-Brown was still alive when you went to Edinburgh?

AE. Yes, and in fact I was one of the first people, he invited me around, and he was actually very nice with me, but oh he was terribly brittle I should say, but not with me though. He had a meeting very early on about in vitro fertilisation, remember R G Edwards I think his name was?

PSH. Yes.

AE. Well he gave a talk. He spoke with this nice north country accent so I thought I've got a friend there. And it's a funny thing, Court-Brown invited me to talk at this meeting, which was really his meeting and I thought that was nice so I just talked about my own interests. But I think what he did, because I was talking about neuromuscular things, I think what he was doing was just trying to keep me quiet, I mustn't be a competitor and that was really it. But actually in retrospect it wasn't a good idea, because we were like a pea on a drum and I think in retrospect David reacted more to it than I did, because he was meeting them all in a common room. I rarely met people in the common room. I was always too busy to go to the common room. I would be going to another hospital or somewhere and I think he found it difficult. You know they were a much bigger unit and when Prince Philip came to open it, he started off on our floor and he was supposed to spend, oh I don't know, 10 minutes with us and about three hours with the rest. It worked out the other way because we were all talking about patients and the Prince loved it. He was terrific and the funny thing is, eventually we said, well you must go now your Royal Highness because they are expecting you downstairs. He went downstairs and we gave him about an hour and then I got a phone call, we are having coffee in the basement so I went down with David and Prince Philip comes up

and starts talking to me again about these kids you see, because he was really interested. He wasn't interested in chromosomes I don't think. He is a very sensitive man you know. He has some weird reputation but not with us he didn't. He was very nice indeed and very supportive. And while I'm talking to him like this you see the wee biddy, very Scottish this, who deals with the coffee downstairs comes up, turns around with her back to Prince Philip and says "Professor would you like a cup of tea", which brought the house down. But it was difficult having this big empire just under us, but we didn't overlap. They took over cytogenetics. But Molly started growing amniotic fluid cells.

PSH. That's Molly Nelson?

AE. Yes Molly Nelson started what I think was the only prenatal diagnosis centre in the world outside the United States.

PSH. Can I ask a bit about that because prenatal diagnosis came in around the 1970 mark was it? And I know you wrote a book about it.

AE. Yes, I edited it.

PSH. So was Edinburgh then just about the first UK centre to do it?

AE. It was the first UK centre.

PSH. Even ahead of Malcolm Ferguson-Smith?

AE. Oh yes.

PSH. That's interesting. And ahead of Paul Polani?

AE. They hadn't done anything then and we made a big thing about it because if you look at that little book. I was reminded of this the other day because the Dutch started their group off after this book. This book interestingly was translated into Russian. The Russians saw the importance of it straight away. In America it had been a funny guy.

PSH. Henry Nadler?

AE. No he came later. It was a guy who published the chromosome work whose name, oh gosh, it doesn't matter. Quite early on, what did we cover here? All the details covering amniocentesis. We didn't have of course placental localisation by scanning then but we had sex determination. That was our big thing because of the sex and growing cells for chromosome studies. Molly wrote about that. We were very interested in the biochemistry because then in those days we thought we could diagnose these conditions by perhaps changes in the amniotic fluid so rather than cultured cells. You know I have a feeling, if I could just, can I just look this up?

PSH. Sure.

AE. If I can just find it. There was a chap who was ahead of everybody before Nadler, before Milunsky. Do you remember Milunsky?

PSH. Yes.

AE. There was a guy before any of that lot and he published an article in the American Journal of Human Genetics and that really was what got everybody very, very excited. People had looked at the odd things you see; Ferguson-Smith published something called Chromosome Analysis Before Birth, but he was only interested in chromosomes. We were doing the whole thing about antenatal diagnosis. Jacobson.

PSH. Yes

AE. Jacobson. And that was in '67. And that was one of the very first things I did when I got to Edinburgh in '68 was to start people working in that field, and I got David and Molly and Charlie Smith then, because he was looking at implications of mathematical points of view. We got a bit of criticism from some pretty senior people at the time. Not on ethical grounds. One guy said "well anybody can grow chromosomes from amniotic fluid cells". Well that wasn't right. It was difficult and of course Malcolm became far the best because he had already practiced so much on other cells; we were new to it and 'why bother sexing these things?' Anybody can sex amniotic fluid cells. Well that wasn't right either. All this was absolutely brand new stuff and people said later well why did David waste all his time on the fluid? Well it's because that's the way we thought it was going to go then, because all these inborn errors excreted funny things in the urine, we thought the fetus would.

PSH. So it did in some cases.

AE. Yes that's right, it did, but it didn't turn out to be the way to diagnose them though, did it really.

PSH. Who was your main obstetric link; was that John Scrimgeour?

AE. John Scrimgeour

PSH. John Scrimgeour.

AE. He's just retired now.

PSH. So was he just good technically? I get the feeling he was actively interested.

AE. Oh he was definitely. He was really the technician and I think he was really more interested in the technology of amniocentesis, especially when B scans came in, real time scanning and of course the chap who had done most of this I think was Stuart Campbell's father, because he had developed sonograms during the war with U-boat detection and so on and then his son who is now in London pioneered all this. Well they taught Scrimgeour, so when we went to a meeting about 1969, yes I think it was '69 in Boston, John gave a very good account of himself with the new technology. We were a bit naïve. I don't think any of us were very ambitious again. Nowadays I don't think you'd do that. You'd publish it and get your name there, but he didn't, he

talked about it at the meeting. The result was within about a month everybody was doing it. Didn't give him any credit. I always felt a bit sorry about that.

PSH. If we come on to after you left Edinburgh, one really important chapter of yours has been your work with the ENMC, The European Neuromuscular Centre.

AE. Yes.

PSH. When did that start?

AE. Well it was very odd really, a chap who I only vaguely knew, Poortman, nice fellow, he phoned me up and asked me if I would talk about SMA at a meeting in Paris, and I said no, I wasn't doing any more research like that now. In fact I was a little bit lost because I'd realised working in a laboratory was never going to be my forte, not the detail, you know I'm talking about doing what technicians do. I wasn't really happy about that. I didn't really know. And anyway he said 'can I come and see you' so he did. He came to Edinburgh and we spent the whole day talking about research and so on which I thought was very odd and then he went. Then a few weeks later he asked me if I would go to Holland and meet some of the senior people and tell them what ideas I had. Well this was very odd because the French were talking about perhaps having something to do with EAMDA and so on and there were the Germans, the Italians and the Dutch and so being like you I suppose, I knew I had to give a talk about what I thought they should do, so I got together about 12 slides. If they were going to have somewhere to do this they should do it. Well I got there and it's rather odd really. The flight was late from Edinburgh, it was in the winter and I was cold and I'd not had supper and they had all had a wonderful supper and a few glasses of wine, and I said to Reinhart Rüdél who was chairing this thing 'I'll just going and check the slides.' He said 'what slides?' I said 'I've prepared a talk.' 'Oh' he said 'you must let the French tell you what you are going to do. They are paying for it.' And I was so upset. I mean I don't need to do this job.

So anyway it really took over because the way ENMC went was the way I'd hoped it would. We were never going to have the money to give grants out which was . . . Their original idea was to have a research committee and they were going to give out, that was never going to work because the value of these grants was going up and up and up. So to cut a long story short I said, what you could do is have workshops and get together people; and then people said, they won't they won't collaborate. Well let's see if they do, then somebody else said we already do all that in Holland. We got all these antibodies at the beginning but it did work. And I think that now we have had 130 or something meetings, and over 2,000 scientists, but the original idea was first of all let's get the clinical diagnosis straight.

Now in retrospect I suppose that seems naïve but I remember we had one meeting on familial ALS and we had done quite a bit of that work, after I retired, after I was emeritus, on ALS in Scotland because I still went on doing things like that and, oh gosh I don't know, out of a hundred families there was only one or two where somebody else was affected, a brother or a parent, pretty rare and they were throwing up these enormous families. That was the

first thing that made me think gosh you know I wonder if this is ALS. Then another one was when they first found a gene for SMA type 1 and in those days we used to move around with ENMC and this meeting was in Boston and Victor Dubowitz was with me, who was a world authority on neuromuscular diseases and these two Americans said we've got families here with SMA and they are not linked to this gene on chromosome 5. So Vic says tell us something about the clinical details. 'We don't have any clinical details.' So this was all getting, come on now, let's start by getting the clinical diagnosis, the differential diagnosis. So we did that in a little booklet, produced a booklet. "Diagnostic Criteria". Secondly when you've got that and you are sure about it, let's do gene search. Thirdly having found gene search let's go back to the families and see how it fits into the new spectrum. And finally, which we're just entering now let's think about therapy. So it was a wonderfully successful and exciting - I would say it was the one thing I enjoyed more than anything else, meeting young people and it was so informal. You went to one but unfortunately I wasn't there so I don't know how it was run when you were there but who chaired it?

PSH. I've been...

AE. You would be chairing it but who was. . .

PSH. I've been to several over the years and the great thing is they were all small.

AE. That's it, that was the great thing.

PSH. And you just had 15 or so people who were all actively involved and it was just ideal for collaboration.

AE. Yes, collaboration and sharing data and material and agreeing on criteria. Yes I loved it, I really did. Now why did I stop? I did it for 13 years. So when did it all start. Oh gosh let me see. I'm just going to look at my notes. This is a lot more than I thought we were going to talk about because I think, Oh '89. And then two years ago I thought it's time to stop now. Somebody else should take over. My theory, you know you can't do it too long. You know what Marcia says is going to be my epitaph don't you?

PSH. I don't.

AE. 'He got bored'. And its true.

PSH. I think doing something for 10 or 12 years, it is right to change after that.

AE. Do you? I think so, give other people a chance as well.

PSH. I know I decided that when I was editing Journal of Medical Genetics. Ten years, I thought well that's quite enough. You can get stagnant after a bit, but that ENMC chapter, I think it's under recognised you know, outside the field. Inside the field everyone recognises it but inside the field I think it's a superb piece of

AE. Well I tried to sell the idea you know Peter, to the College of Physicians, I wrote a thing for them, we had a little meeting, they weren't interested. I tried to sell it to the RSM, they weren't interested. You see I think, and I hope I'm not going to say something impolitic, but I think there's not much in it for them. The Medical Research Council could do it but I never approached them.

PSH. But in terms of output from a relatively small amount of money it's amazing.

AE. Oh it's peanuts. Peanuts. I didn't get paid. I didn't have a salary. I just got my travel. Michael was paid but we didn't have him at the beginning. We used my secretary in Edinburgh.

PSH. That was Michael Rutgers.

AE. Yes. He's left now.

PSH. He was a really good organiser.

AE. Terrific, but at the beginning we didn't have him, we did it with a secretary in Edinburgh and Ysbrand's secretary there. It didn't really work, Michael came along and Michael was like a son to me. He really was and he would say "What do you think Alan?" and I would say "oh I don't know." "well Victor's being difficult." "Oh well I know he's difficult but he means well". But he was just the right sort of person for me to work with because I like benign people. Let me show you something. You might find this of interest. They had a big farewell for me which was really touching and he put this together for me 'The History of a Research Director'. Isn't it nice?

PSH. That's very nice.

AE. Yes a really nice chap.

PSH. Very nice.

PSH. But the beginning was awful because the Dutch people all spoke Dutch and I didn't understand what they were talking about and it was trying to get them to take it seriously. They all do now of course but you see, I would love to have seen, as you said, that model for other diseases. I mean there must be millions. You know there's this SADS, what do they call it, Sudden Adult Death Syndrome. And of course they are nearly all channelopathies, long QT syndrome and so on. So I did write to them a couple of years ago and said I had a bit of an interest in this, because a disease I am interested in leads to sudden death, wouldn't it be a good idea to . . . no they weren't interested and then I tried the respiratory people. They weren't interested. And I think there's a real problem, if somebody said to me Alan, would you like to do it now and there's a bit of money and you could, I would. I would start all over again because it worked a treat.

PSH. I suspect as you say, maybe it doesn't give much chance for any one person's ego to develop.

AE. None at all.

PSH. It just spreads it out among younger people.

AE. I think that could be a reason. I thought that was lovely though don't you?

PSH. Very nice.

AE. And then I set up this RSM section in medical genetics, that was another thing out of the blue which is now finished. So if you think of something else I can set up I love doing things like that. You know setting something up and when it is going, that's it.

PSH. Hand it over.

AE. Yes. I have a habit of doing that.

PSH. Tell me a little bit about your books.

AE. Oh gosh.

PSH. Did writing books just come naturally to you?

AE. No, I would say the opposite. I mean I was very poor. I went to a very good school, as a scholar so it didn't cost my parents a penny, but I never took advantage of it. This is where something's wrong. When you can send a kid to a public school who comes from a working class background. He is never going to be tolerated by his peers. Never. You are out of it and so I used to roll my socks down, take my blazer off, put it in my school bag, take my cap off and my school tie and never did any home work and so on. Played in the street at night. When you think about my colleagues in school, their fathers were doctors, lawyers, dentists. They went home, they had books at home. We had no books. You know, totally different. And I was quite slow to learn to write, but then I had a unique experience when I was in the Army, just before I came out, BBC 3 started and at that stage, they were looking for people to write things so there was a short story competition and I won it. And I thought oh here's my career now. This was before the Colonel told me you should go and go to the University, but of course I wrote millions of other short stories and none ever got accepted, but I have always loved writing. I write poetry and I get them published. I have had a reading at the Edinburgh festival. Did you know that?

PSH. I didn't know that.

AE. And I've even written Haiku, Japanese poetry, so I have always loved writing and it gives me a great thrill to do it. But it was difficult in the beginning and it didn't come naturally. It's become a challenge. I've got something else you may be interested in, I dug out. I'm glad you are asking me about this because this is a side of my life I'm most proud of.

Well I had an article here. I haven't given it to anyone. I will have to send it to you.

PSH. That's OK.

AE. The thing is, quite a long time ago, the BMJ asked me to write an article about books you've enjoyed and I think they thought I'd write about genetics. I wish I could find the thing. So I wrote this and I called it Love, Lyrics and Logic and it was all about literature and poetry and the editor wrote back and said this is brilliant. This is wonderful. I wish there were more scientists were like this. Well that was the only positive reaction I got. The rest were awful. I mean Michael Oliver in Edinburgh said 'Why did you waste your time doing all this'. Oh so I just, it's not there is it Peter. It's not under this.

PSH. I don't think so. Not to worry. We'll find it afterwards ["Lyrics, Love and Logic" Brit. Med. J 2: 1280-1281 (1979)]

AE. Ah well, its not important. So we've always had something else we've not talked about. I've always had two lives you know and they don't cross over. I've had the life in the arts. I'm a member of the Arts Society and all sorts of things and I paint. I've painted all my life and had exhibitions and they are in various galleries now, so I have always had these two lives. They don't overlap at all. I don't paint about genetics and my genetic colleagues are nothing to do with my art colleagues. They are totally different people. They are just as competitive though. They just are you know. They argue the toss about, well I've got an exhibition in Cork Street next week. You see that's the big thing. That's like you saying I've just been made a Fellow of the Royal Society. But I've always had these two lives and I think that's probably helped me a lot. It's like two worlds. I really enjoy it now that I am older and I've got more time to do it.

PSH. What kind of painting do you do?

AE. Oh dear, well, I'll show you around when we've had lunch. There's one. That's not typical. It's called 'My Australia', that. I would have to explain it to you how it is. But usually I do portraits. That's Marcia and myself. But these are just photographs. The originals are in the bedroom. Portraits and landscapes, seascapes. I love the sea. I'm obsessed with the sea. But I have loved that all my life. I love painting; I get totally lost and I get very angry with people who interrupt me. Someone said you are working on two different . . . Do you know what the problem's been. Do you want to switch this off because it gets a bit personal. No you don't want to switch it off. Better ask me over lunch.

PSH. We'll do that over lunch. Can we just go back for a moment.

AE. Back to genetics.

PSH. I mean your 'Elements of Medical Genetics' [In 2008, in its 40th year and 13th edition, awarded BMA Best Student Textbook Award] was the first book and then your 'Antenatal Diagnosis'.

AE. Yes. You don't want a list do you?

PSH. No I don't want a list. Then your book on Duchenne, that was really valuable. At what point did the big Principles of Medical Genetics take off?

AE. Well, that was when I was at the American Society for Human Genetics, I think the only meeting I had ever been to. I saw Aubrey Milunsky and I said I was thinking of doing this book, a big book on medical genetics that could be a reference book. He said oh, I'd like to do it with you. And David Rimoin is a very good friend of mine. We used to have rooms opposite each other at Johns Hopkins. Was he there when you were there?

PSH. He had just gone to California.

AE. Oh California, because he went first of all to St Louis.

PSH. Maybe that's where he'd gone.

AE. He went to St Louis first of all. Well anyway I said alright Aubrey, can I think about it. And I went and sat with David. And David said "What's going on?" I said "You don't want to know". David said "Why". He said "I'll do it with you". I said you wouldn't David. "Yes I will" so that's how it started and he is a wonderful chap to work with and I have enormous respect for him and that's how it's gone on. Our new edition's about to . . . well you know. Presumably you've done another chapter. I don't have anything to do with it now. There's a new edition coming out now. It'll have to go on CD Rom. We can't go on like this.

PSH. How easy was it to put that together across the Atlantic?

AE. Much easier with David Rimoin as a co-author, editor I should say because he corralled all the Americans and I did the Europeans but I notice now there are far more Americans than Europeans, but of course that's in the nature of the beast, there are more of them now aren't there?

PSH. Yes.

AE. But I can't take credit for it, I don't do much with it at all now. Just the odd thing. It's usually semi-political. They ask me what about this. Do you think this is the right way to do it and so on. It is a good book and I use it quite a lot. Looking things up for instance, last night we watched a TV programme and there was a child with tuberous sclerosis. Did you watch that programme?

PSH. No I didn't.

AE. And I vaguely remembered they didn't get just one tumour in the brain, they often had many, so what was the point of operating. Looked it up, quite right. They often have lots. There's no point in operating. And so you know I still look it up for things all the time, so it's good from that point of view.

PSH. When did you start getting what you might call a historical interest?
Was this through Duchenne?

AE. Through Marcia. It was through Marcia, and Marcia and I met in '87, and she was a librarian at Duke and I was doing this book on Duchenne and I happened to say to her one day, they had a wonderful library there. Oh Boy. I said I wanted, you said there's nothing done about Meryon. I said no no no, hardly anything. She said I'll look it up. I'm interested in genealogy. Anyway we had a very slow protracted romance. Which went on for well over a year because I really didn't want to get married. Not again. I had burnt my fingers and I was quite happy on my own by then. And I had good friends and so on, so I didn't really. Well anyway she came over to Edinburgh and we drove up to the Highlands because her parents were Scottish, her father was Scottish and we went up to Inverness. My son was working there, to the library and the girls said "Ah Marcia Lavine, how nice to meet you". I said how do you know her! Of course it was because Marcia is a member of the Highland Genealogical Society. So she is a past master at collecting and doing family histories, and all that work to do with Edward Meryon is really largely Marcia's. We went to France a couple of times. She chased up all the Huguenots. We became members of the Huguenot Society and that is how it all developed. She traced it back to 1685, the family, and so it's really her work. She was the one who did all the slogging of, going through church baptistries and things like that which I knew nothing at all about, being a geneticist.

PSH. Have you any books on the go now?

AE. Well we've just finished one. You know we did the one on Medicine and Art.

PSH. Yes.

AE. Well they just sent me this as a set up for the new one. Which is 'Surgery and Art.'

PSH. Oh that's

AE. It will come out in about a month's time

PSH. That's good. Surgery gives you a lot of artistic scope.

AE. It was better. Well I didn't want to do it, Peter. I don't know if you know Peter Richardson the publisher?

PSH. No.

AE. A very nice chap. He said surgery will be better Alan. I said I know nothing about surgery but once I started into it it was terrific. I mean you've got all the excitement of when anaesthetics came in, antiseptics, asepsis, all the technology there now but even before that, how we developed from Ancient Egypt. And you can follow surgery much easier than, well medicine didn't really do much you know until we got antibiotics. It really didn't do much. I mean I can remember as a kid being wrapped in brown paper. You

can't imagine that now. You know that's only one person's lifetime ago. Brown paper put around me in the winter and stitched up because we didn't have baths of course. I mean! But surgery is just incredible so I hope you'll like it. I'll give you a copy to review.

PSH. I look forward to it. Just to finish, I have been asking everyone I see two questions, so I'll ask them to you. And the first is thinking of all the different things you have done in the genetics field, is there one which kind of stands out that has given you most pleasure, you are most proud of?

AE. In genetics?

PSH. In genetics now I am thinking. Which would you choose if you had to point to one.

AE. ENMC. The setting up of ENMC. I think this created more collaboration in Europe than we could ever have done otherwise. And the world and people from Australia talk about ENMC. People from India talk about ENMC, and America. It has been the thing I have perhaps enjoyed most.

PSH. Then the other thing I have been asking everyone is which person would you feel has had most influence on your work in genetics at any point along the way.

AE. Robert Platt, because he got me interested and he was a genuine physician with a great love of patients. He always put the patients first. Always put patients first. And that I felt was always extremely important, not the gene, not all that business, but the patient. What's it going to mean to that patient and his or her family and all the implications of that, and Robert Platt inculcated that in us as students and that stayed with me and both this book and the one on Medicine and Art are both dedicated to him.

PSH. Now I said finally, but there's one thing which I have forgotten which I did say I was just going to ask you about and that's your views as to how genetics developed in Britain during this time from the beginning of the sixties.

AE. Well the funny thing is when I came back from America there was virtually none and I went to Great Ormond Street and saw Cedric Carter. He and I became very good friends over the years. I mean very close friends indeed. I have stayed with him and he with me. We were very close friends and he took me under his wing. But his way of counselling, I have to say wasn't the way I saw it. He had been bred in a eugenic philosophy. He wasn't a eugenicist, please don't misunderstand me. He felt 'Oh well they shouldn't have any more children'. They shouldn't do this whereas, I don't know why, but I developed the concept that it's up to the parents to decide, whether they are Catholic, whether they are Buddhist, whether they are Wee Frees. People like this have different attitudes to disease and it's up to the parents and I have never felt deep down I have never felt that Cedric and I had the same philosophy for counselling. To him, it was make the diagnosis, give them the risks and of course in those days there was nothing else you could do. So when I came away from one of his clinics early on I thought I can't do it this way. I want to do it more as a branch of medicine than

anything else, not as a branch of science, a branch of medicine, clinical medicine and ultimately clinicians will be doing all this and they will be the best people and I always felt this quite strongly. If you are a clinician dealing with children with cystic fibrosis, you are the best person to give genetic counselling. You know the treatment, you know what it's going to mean, you know the prognosis. A neurologist dealing with Huntington's chorea and neural disorders is the best one to give counselling. We can do it but unless you are specialist like you in Huntington's chorea or me with muscular dystrophy. I mean if I was presented with a case of cystic fibrosis I can't tell you the details of the prognosis now. I would have to keep going back to see what's he saying in the book. So this was my philosophy that it should now start to go more and more towards the professions themselves. There will always be a place for geneticists obviously, especially dysmorphology, which is very specialised, and there will always be a place for these laboratory investigations, but at the clinical level I would hope most of it will turn more and more to the physicians themselves. I can even imagine a day when a surgeon will be able to do it but that's sometime away.

PSH. No, they are getting quite good in things like polyposis.

AE. Yes of course, I see.

PSH. But how do you think it actually happened? One of the puzzles I have been trying to work out is how it happened through the NHS for instance. How did people manage to persuade the Department of Health to create . . .

AE. Well I was in Scotland, so that's a wee bit different from in England and Wales. I don't know what the situation was there. But in Scotland we did it through the Postgraduate Dean. And one of the first jobs, remember how we used to call them registrars. They are now SPRs. You had to get them registered for training and we were one of the very first people with a little blue book who had a person in the position to be trained in that way, and he and his team came to see us and that got us then involved in the NHS, in the south east regional hospital board as it was then, and that got us involved. And then the MRC, the NHS itself, directly the NHS, I don't seem to remember ever being directly involved myself. That must have come along later. All this business now about the, what do they call them, the Gene Parks, is that what they call them?

PSH. Yes.

AE. This is all very recent. I never got anybody from the NHS writing to me and saying you know, tell us your thoughts about this. We didn't seem to have that relationship with the NHS in those days.

PSH. Would you say for instance in England would it have been Cedric as the key person, or Paul Polani? Who would have kind of been the ones who

AE. I would have said it was the next generation to be honest. I would have said those chaps sowed the seeds but the ones that got it to grow and mature with relationships and the NHS was actually their descendants and I am thinking now about people like Michael Patton. People like you of course.

PSH. Rodney.

AE. Yes. Absolutely. They were the ones who did it. I don't think at my level we really got that involved. Of course I don't know what Paul did. Paul was always seen as a cytogeneticist in any event and I don't remember how Cedric got involved with the NHS. I may be talking out of turn but certainly in Scotland we had no relationship with the NHS and nothing directly, except for training.

PSH. And on the university side, again were you conscious of there being any systematic programme to develop medical genetics across the whole country?

AE. Well there was in Scotland. That was due to Edinburgh, and although we had all that trauma at the beginning of trying to find our identity, after two or three years we got a lot of support there from the Scottish Health Board, as it was, and the University to develop clinics and things like outreach clinics and I think Scotland was ahead of the field. Of course it's a smaller country, 5 million, and separated, so it's easier to do things and racially homogeneous and I don't know how on earth you could do these things in Birmingham. Very difficult.

PSH. Are there any other things that I have not asked about that you think are important that you want to put on record or have we covered the main things, at least in genetics.

AE. Yes, I think from my point of view. I don't think I've got much else to say. It has been a very, very exciting career. I really have, I have enjoyed it enormously. The saddest thing, if I can end on a rather sad note, because when I came down to Devon the consultants at the RD and E [Royal Devon and Exeter], which is a very nice modern hospital in Exeter, got me to see patients on a Friday with various muscular disorders where they thought they knew a little bit about it. And I did this for several years. Didn't get paid. In fact it cost me because I had to pay to park. And I wrote the letters to GPs and then when I was 73, out of the blue I got a letter from the Health Board saying they discovered that I was over 70 and I couldn't see patients on the NHS any more. Despite the fact that I had done it for nothing. And I told John Walton socially one day and of course he wanted to bring it up in the House of Lords, something like that, because here they are crying out for doctors and here's one that is doing it for nothing and I wasn't allowed to do it. They said I could do private practice but I had never been involved in private practice. I wouldn't know how to start it anyway. So I think that was the most, I'm 77, that was four years ago and that was the most disappointing thing in my career, to hang up my stethoscope and I couldn't use it ever again. And that was upsetting, but I can see now that really perhaps in age all you've got really, hopefully, all you've got is wisdom, but the technology goes. You don't know the details now and you can't know what sort of function MRI you want now, all that quantitative MRI. You don't have it at your fingertips now. But I was disappointed about that, but of course I was doing the ENMC and that was a great success. And I think RSM has been a success in a different way. We've got that going off now. We've got some exciting meetings coming up.

So I think it has been a nice note, I don't want to say to end on, but you know what I mean?

PSH. Thank you Alan.

End of recording