

Helen Hughes



Personal Details

Name	Helen Hughes
Dates	10/04/1944
Place of Birth	Tudweiliog, Wales
Main work places	Cardiff, Toronto
Principal field of work	Clinical Genetics, Dysmorphology

Short biography

Helen Hughes trained in Paediatrics in UK and Toronto, moving into clinical genetics and becoming responsible for services at Toronto Sick Children's Hospital, as well as initiating the system of outreach clinics for Ontario. After returning to Britain she developed genetics services for north Wales and made notable contributions to UK clinical dysmorphology.

Interview

Recorded interview made	Yes
Interviewer	Peter Harper
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INTERVIEW WITH DR HELEN HUGHES, 27/03/2013

PH = Interviewer (Peter Harper)

HH = Helen Hughes

PH It's Wednesday March 27th 2013 and I am talking with Dr Helen Hughes at her home in Llandaff, Cardiff. Can I start more or less at the beginning, Helen, and ask where you were born and brought up?

HH I was born in Tudweiliog, a village in the Llyn Peninsula in North Wales and essentially lived there until I came away to university, to the big city of Cardiff, when I was 18. And my family had lived in that area for some generations I think - not exactly in the same place but in the general area - both my parents.

PH So you were brought up with Welsh as your first language?

HH Oh yes, yes.

PH When did you learn any English?

HH We lived in a holiday area so my mother used to let the house furnished for the visitors that used to come mostly from Liverpool, Manchester, Birmingham to North Wales so I know I communicated with kids and played and went on the beach and stuff. I was unilingual Welsh and they were unilingual English but I know I played with them all Summer because some of them used to be returns. But officially you started official English lessons at the age of 7 and that was when you So the first two years at 5 and 6 you were in, literally everybody was Welsh speaking anyway, so you had very few people that were English people that had come in and then you officially started at the age of 7. And we were all in it together because we were all Welsh speakers starting to learn English at the same time.

PH When you were at school was there anything that pointed you in the way of Medicine - that kind of made you go in that direction?

HH I think that probably one of the influences was that I had about 4 female cousins on my father's side who were all in nursing and I used to go on holiday some miles away for about a week somewhere to one of my aunts and uncles and my cousin then was training in Bangor and used to come home on her day off, so I think I got into hospitals and medicine on that sort of level; in school I was actually better at the Arts subjects in fact, although I was not always very creative at all, so I hated having to do essays as you probably will realise later on. So it goes way back but I think the influence of - I hadn't visited many people in hospital or anything like that - but I think the influence of hearing stuff that was happening on wards and what was happening with people and I was actually quite interested; I enjoyed Biology and it seemed to - you know, you went through phases of things you wanted to be as you grow up that have nothing to do with any common sense. Of course in the British system then you had to pick so early to do your A-levels. So you had to pick at 16 and all my science subjects I just scraped through. But I was in a very small school and I remember we had to do Physics and I got something like 50% odd at O-level but in the holidays I went up to this teacher and said "I've got to do Physics if I want to do Medicine" and he said "Oh we'll cope somehow". There were just two of us in the sixth form and the other guy actually ended up doing a PhD in Physics and he is a lecturer in the University of Glamorgan; so I basically had two private tutors and the key thing I learnt in Physics, which was key to later on in dysmorphology, was he didn't teach me how to do Physics, he taught me how to approach a problem and figure

out how I could do this, either I think I could do if I try, or forget about it. And I used that very much, you had to cull that with kids you saw in dysmorphology and you just had to put your efforts where the greater returns were in a way, and who to follow and that sort of thing. And I can remember this Physics master coming back after the first paper in A-level Physics and he was outside and he said "Did you do question 1?" and I said "No" and he said "Thank God! You never would have". So it was key teaching that stood me in good stead really.

PH You went to medical school in Cardiff?

HH In Cardiff, yes

PH And what year was it that you graduated?

HH I graduated in '67.

PH Cardiff was a pretty small medical school then.

HH Yes, I think there were about 60 of us in the year. And we were odd in our year because Cardiff had quite a number of women in most years and we stood out because there were fewer of us than average. I think there were about 15 out of 60 or 70 and actually the proportions then were usually much higher. It was a smallish group and in smallish groups you got to know people fairly well and you did various firms and rotated and that sort of thing.

PH Was there anything during the medical school course that pointed you to either paediatrics or any other particular direction?

HH No, I think what I wanted when I graduated - I thought I was going to do obstetrics because I enjoyed the obstetrics bit, and I went up after doing my house jobs in

Cardiff the place to do obstetrics then was Liverpool and I got into that programme in Liverpool and after about 3 weeks I thought "this isn't for me" because the gynae I actually found frankly boring, it wasn't very challenging.

And I was no surgeon. Obstetrics for me was - things used to happen too fast and too quick and I was not the person that you would want to reach in an emergency and I needed to think things out so I figured that this really isn't the specialty for me. So I then drifted. What hadn't I done? Alder Hey was just down the road and I thought "I'll apply there" and I really, really quite enjoyed it and I thought yes, I really like working with kids. And that's why I ended up in paediatrics.

PH How long were you at Alder Hey?

HH I was there for over a year. I accepted six months and then extended it by six months. And then I had literally to decide, now what? And I had no intention of doing any membership or any higher exam and I thought well, what shall I do? Maybe I will go off for a year - maybe to Canada for a year - you know, what you do when you can't figure out. There was a guy on my firm dealing with kids with PKU - Freddy Hudson - and I just asked him did he know anybody in Canada or where to go and he knew Mike Partington through PKU who worked in Queens, Kingston and he said why don't you write to him and see if you can get in there. So that's what I did and I just went to Kingston for the year and that's how I landed in Paediatrics.

PH And how long were you in Kingston?

HH I was in Kingston for a year and then I moved on to Toronto.

PH Where did Edinburgh come in?

HH What happened then was I was now doing a residency in Paediatrics in Toronto and of course in the Canadian system, like the Membership or Fellowship, there was an exit exam and everybody was working for a fellowship and I hadn't done anything. I hadn't done my

membership or a first part or anything at all and I thought well everybody else is doing it and during the rotation it just happened that there was an elective where you could do whatever you wanted for that month and I saw there was a genetics department there and Noreen Rudd used to come on the ward just to see the children. There wasn't really a consultation. She came to see kids because she picked them out in the lab and I thought this was sort of interesting.

PH She was doing cytogenetics?

HH She had been there really just to run the pre-natal programme. She was a paediatrician and had been hired to - really they were starting the pre-natal programme, including a lab, and she had been trained in the laboratory as well. So she actually came to run the pre-natal lab. But she was a paediatrician and had worked in Sick Kids as a paediatrician and was qualified, so she then evolved her own role and began to become clinically involved because there wasn't really ... she in fact was the only clinician in the system that I was aware of at the time. There were other people that maybe had been through pathology and things but not really in the way that we look at it today. So I thought if I could do a month rotation in genetics - and I thought "this is it". Loved it. So then I wondered "now what do I do?" because I was going to come back to Britain to carry on in Paeds. I wasn't sure but there was no fellowship, there was no money, and I just kept on; I talked with Lou Siminovitch, who had responsibility for the clinical department although he was at the university and so I kept on begging and begging and going back and forth, asking was there any money, was there any hope of doing something and I am not quite sure where they got the money but they - I was ready to book my flight back actually to figure out what am I going to do and they said "we have found money for you". So I cancelled everything and then literally did a fellowship in genetics and extended it and during that time I got my act together and I came back and did my first part, which was awful because I had to do everything and I thought if I fail it I am never going to bother to retry it. But I got it, and then I did my second part membership, did the Paeds one, in Edinburgh because I was now doing Paeds, and did the Canadian fellowship all in 1973. I just did them all, and was fortunate enough to get them. And it was then that I thought well, now what do I do? And they were discussing about expansion and where they were going to expand. There wasn't a hard core clinical service. The metabolic side was more big really but through Paeds and this is where I got to know Andrew Sass-Kortsak who was more metabolic but he also was on liver, Wilson's disease. This was his area of expertise and he had drifted into genetics through that route. He was looking to expand that area and we were talking about it but nothing was happening. And I thought I would come I thought well, I've got to look at the British scene. And there was Cedric Carter in Great Ormond Street and Alan Emery in Edinburgh.

During my second part membership I went to see Cedric Carter and of course I hadn't got my result. I had done my exam but I hadn't got the result. And there I was from Canada, over for literally two weeks, and he said well, come back and speak to me when you know you have got your fellowship. So then I went to Edinburgh and Alan Emery was much more encouraging and interested and he had his register and stuff going and I guess he began to see possibilities. So I went back to Canada and a week later I got my result. But already now I had started dialogue with Alan Emery because he had initiated that. One thing I should just say was interesting in terms of my interest in genetics. The only genetics I had done was in high school during my A-level zoology and I had really enjoyed it - the sort of Mendelian bit - and I obviously, the biology master came back to me years, years later, literally about 10 years ago or something, I met him in some reunion, and he said "I always remember" and it's funny I think because it speaks to my interest because I was always one of these people that could cram, you know, I could just do nothing or cram. I could just get it together for an exam or something. That's the way I've always worked. And he said - there were 5 of us in this

zoology class A-level and we were doing something to do with Mendelian inheritance, I can't remember what, and he asked at the end: "So, did you all get it?" And I said "No, I just don't get it". And he thought over the weekend well, I obviously was getting most stuff, and he thought if she's not getting it I have really got to re-explain this and he was working on how to re-explain it all. But on Monday morning I came back to him and said "You don't have to go through it now, I've got it." So I had obviously been interested enough to read it which I know normally, if I wasn't interested I wouldn't have bothered. And the one book that I have - you had to pick, like, like a school prize for a book - and the book was Elementary Genetics by Wilma George. In fact she was later lecturer for Carol McEwan in Cambridge. I've got it here somewhere. It was all to do with Drosophila and whatever. But that was the book that I had got for myself. But in between that and when I did this fellowship there had been nothing to do with genetics at all.

PH So how long did you spend in Edinburgh?

HH So I went back then, I was in Edinburgh let me see, how long? Probably between 12 and 18 months. And it was during my time in Edinburgh - because now I was doing the register - and during this time in Edinburgh - I had been there probably about 6 or 7 months - when Sass-Kortsak wrote to me and said "The job we were thinking about has now materialised and is more to do with metabolic but we would be interested if you applied". And I knew from conversations, you know, that if we worked things out that something would work. So it was really difficult then because in the British system at the time I really would have had to go into research, which I knew just wasn't me, or to get a clinical job; you had to go back and do an SpR in Paeds with an interest and I knew that in the North American/Canadian system, because at that time the Canadian College of Medical Genetics, people were talking about establishing it and the whole thing was going on in the early to mid 70s and it was like a wide road and a narrow road, you know, and I had enjoyed my time in Canada. But it was a biggie, so now do I go back and do what I'd like to do, or do I sort of struggle in this system? And I decided to go back. So I went back in 75 and it was on a staff position. But it was mostly to deal with more metabolic, Wilson's, amino acidopathies, all of those sorts of things, rather than standard, more clinical genetics. But of course I knew the genetics people, and I had spoken with them, so it was agreed that I would also be involved in clinical genetics as well. So again, in a way, I carved a job as well and again over time in fact that clinical part took over more and the other one diminished. So I mutated again - the system allowed me to do that - over the years in Toronto.

PH And this was all based at Toronto Sick Children's?

HH Yes, it was. There were cytogenetics laboratories in a couple of other hospitals nearby but the clinical stuff was really all based at Toronto Sick Children's, yes.

PH So who were the key people in genetics and medical genetics at Toronto Sick Children's then?

HH Right, the key people, the one that I sort of related to, mostly because she was the only paediatrician, was Noreen Rudd. So that was the clinical. The one that I was directly responsible to was Andrew Sass-Kortsak and the metabolic genetic side that was beginning to develop. And then the other people that were there, that were working, obviously Peggy Thompson, Diane Cox, Ron Worton - he was mostly more laboratory-based and was actually just beginning to take over to become a cytogeneticist in a way, to take over the cytogenetics laboratory, because his background, I believe, was in biophysics, and he had been involved with Lou Siminovitch. There were a number of people in the University of Toronto that we would go and visit and deal with. And I have probably forgotten some key people here now. The other person that was affiliated - he was based in the developmental disabilities group - was Joe Berg - but he used to come into the department.

PH Let me ask you a little bit about Peggy Thompson. She must have been quite close to retirement at that point.

HH Yes, I think she is now well into her 90s so let me figure it out. How long ago was that? This was late 70s so she would have been late fifties, early sixties, something like that, at the time, yes.

PH Have you any particular memories of her?

HH Very much so, yes, I do. This was the era when - again, I've got to pick my words carefully here - this was the era where Toronto essentially was dominated by non- clinicians in clinical genetics, when things were changing rapidly when these Johnny- come-latelys - paediatricians - were beginning to elbow their way in and, because they were medics, would be taking over. That sort of ethos was there at its height and it was a very, very difficult time because there was this constant clash of cultures, if you wish. People that were very, very able - I had huge respect for their abilities - but there was this huge clash of cultures. And so really one was caught right in the middle of that because it was just like change was happening, and it wasn't always embraced, and maybe not always done in the most - you know, how things happen. And so at the same time there was the establishment of the Canadian College of Medical Genetics, which is believed to be the first. It certainly predated the American College, and there wasn't such a formal arrangement in Britain, although the clinicians in Britain were very strong because there was a Clinical Genetics Society. So they certainly were more in the forefront. So it was an interesting time and quite a lot of stuff was happening around then and there was also then within The clash between metabolic, which was actually quite prominent within Canadian genetics because of the influence of people like Scriver, who was very prominent in the establishment of the College and there was a number of people with more metabolic background that were involved much more in genetics whereas in the British scene they were more firmly in the paediatric camp although there were lines that crossed. So in a way there was a 3-way - well, I wouldn't go so far as to call it a standoff - there was a 3-way culture and of course in Toronto that was quite prominent because the other person that was leading the metabolic group at that time was Sandy Lowden and he had done a lot of work on Tay-Sachs screening and so on. So that was being established and screening procedures and things were going on. And there was one other paediatrician - Bill Hanley - that was running the PKU clinic. So I related quite a bit to him. This was during my metabolic phase. But what was interesting also - this was in Toronto - this is how you evolved - there was a paediatrician, who originally came from Llanelli, called Geoff Sherwood, who has passed away now, and Geoff was a unique character, very, very able and way ahead of his time in many ways, and he was the one that could make metabolics fascinating to residents because he had a way of explaining metabolic pathways in a way that nobody else could make interesting. And he was actually employed as a paediatrician and because of his abilities and innate thinking about metabolism he was really also evolving into metabolic work and that allowed me - you know, we almost did it between us - he was evolving into metabolism whereas I was quite happy to shift out of it and evolve into more standard clinical genetics. And the other person that was appointed by Sass-Kortsak at that time on the metabolic side was Rod McGuinness. He came quite fresh from - I think he was in McGill - and had worked, I believe he had worked with Scriver - and then he came and joined the metabolic group. So that actually again allowed me just to drift and of course there was this gap of clinicians other than Noreen trying to hold the fort. And then she and her husband, David Hoar, who was in the university department, they over this time were head-hunted by Brian Lowry in Calgary. So they actually moved to Calgary in the early 80s - and so I again was the only clinician and took on some of Noreen's responsibilities. So things just evolved.

PH How did you become especially interested and involved in dysmorphology?

HH Again, I think that was the bit that I think really got me into genetics. And it's amazing actually, and again I suppose this is half off the record and I won't name the person that did it - I haven't actually named this person - but I know that they said a great statement at one point - this was getting on a bit later - that they couldn't see the relevance of dysmorphology in clinical genetics. And that was when I thought "If that's the way it's going to go here this is where I am going out. It was just - it had to be - but they saw it from this metabolic angle, you know, from a gene and an enzyme, and somehow they hadn't translated that, that this had to be the way that everything worked in a way - the simplified way. And so for me that was the key thing that got me involved and I think that was for quite a few people who came to the paediatric route probably, this was the interface and then you realised you'd got to learn all the genetics stuff which became more and more of it as all the DNA era came in and in fact it was quite interesting. I got caught with a few people when they were establishing the Canadian College of Medical Genetics, there was a group of people quite correctly that were so-called "grandfathered" in and there were just a few, about half a dozen of us, that were just on this fine line. Maybe you could get grandfathered (or grandmothered) or maybe you wouldn't. And I think in retrospect I was pretty mad at the time because I didn't get grandmothered in, but I think - and I am pretty sure I am right - that I was in the first tranche that did the exam and it wasn't a half bad thing that I had to do it, because I literally - that is when I grappled with Bayesian risks and all of this stuff which everybody - you've just got to do it. And I must admit that if I hadn't had to do that I would just have been skating on thin ice. I still was skating on thin ice really because again I am one of those people that if I am not interested I am not interested. But it wasn't a half bad thing to do it and so I did the exam and that would have been in - when did I do the exam? - I think it was '77 or something like that. It was the first group that did the exam. Pat McLeod and Su Li Yong from Vancouver were in that group. There could have been others but I don't remember them.

PH How was dysmorphology developing in North America and Canada at that point? I mean, you must have seen it, if not start, at least from a very early stage.

HH Yes, I did. And my first memory actually was in fact, the one who was in Kingston was Mike Partington, and during my time in Kingston I remember going with him to the various institutions which actually, when you look back on it now, were quite chilling in some ways. He was involved, really, in trying to look and in trying to figure out what was the matter, because most people just didn't have a diagnosis. And I remember distinctly - it was during that year in Kingston - I think it was a Canadian Paediatric Society meeting was being held in Kingston, and Michael Partington got David Smith to come in to give one of the talks and that was my introduction to David Smith. And so my interest in that aspect got nurtured a bit during that year and then, when I moved to Toronto, and then saw Noreen on the ward, I think that happened, and then I started going to the American Society meetings and I am not absolutely sure when the David Smith meetings got started but they had been going on. I wasn't at the earliest ones but I started going - I can't remember when I started going. Probably the late seventies, early eighties, whenever.

PH Did you know David Smith at all? Or had he already died?

HH I didn't know him. I met him. And the other person, during the course of one of the Smith meetings, that had worked with him was Tal Thomas and I remember meeting him at one of the I didn't realise he was in the US. Because I remembered him from Medical School in Cardiff and so I met David Smith more socially on a couple of occasions but I never actually directly worked with him or anything like that. But I certainly heard him speak a number of times, yes.

PH The other thing from Toronto I wanted to ask about was the Ontario outreach programme. At what point did you start developing that?

HH Well what was happening on that - and I was trying to get my chronology in order here - in fact I had given a talk but it was on an old computer and I can't retrieve it. But what happened was that they had established an Association of Genetic Counsellors of Ontario - just the people from the 5 university centres that had got together: Toronto, Ottawa, Kingston, London and Hamilton - it had been going on for some time. I can't remember if it had started before I left Toronto, but it was in that time and I came back and within weeks of coming back I was at their first meeting. And what happened was that an organisation known as the IODE, which stands for the Imperial Order of the Daughters of the Empire, had approached I think Howard Valentine originally or Hubert Soltan, and they had money for some project to do with children. And of course the President of the time was living in London, Ontario, and was quite a remarkable lady called Elizabeth Currie. And I think that Hubert and Howard - you'd have to ask them exactly how it came about - were aware that there was some clinic in the US - I am not sure where - that had started something of an outreach clinic, that there was one other somewhere in the US, and I am not even sure who had started it or what. And they thought why not think about doing an outreach clinic and putting the money towards this. And so they brought this as a proposal to get everyone involved in Ontario, and the expenses would be funded by this IODE group. And so they wanted somebody to literally take it on as a clinical geneticist. Everybody was too busy - you know how it is - and I was the new kid on the block and hadn't actually started getting busy and I thought to myself well this might not be a bad way of really getting to know the other people in Ontario and getting into something and so I said OK, I'll do this. And then the person who was - she might have been the Chair or the President of the organisation - at the time was Nancy Simpson, and so together with her we started meeting with the IODE to really figure how we were going to put this in place. And the reason it was picked for Sudbury was there was a very, very active lady - Kay McKenny - who was quite prominent in the organisation and I remember being there when she put out this case for Sudbury to be selected as the centre, to be the one to go to, and Sudbury, people know it is a pretty desolate landscape actually with nickel mines and everything. I think it is true that the moon walkers trained there - but she made Sudbury look absolutely fantastic, I remember, and therefore it was the IODE, because they needed a local organisation and we knew we needed some helpers, some people, and so that's why it went to Sudbury. And so we then needed, well, we really didn't know how to do it, I think maybe Hubert had some ideas from what he'd gathered, but certainly from my recollection it was just done from nothing. And so we started talking, and talking to the other geneticists, and would everybody give of their time and how would we do it, and it then became clear we needed somewhere to hold the clinic. And the reason was there were two main hospitals in Sudbury at the time, and there was a bit of tension between the Catholic hospital and the non-Catholic hospital and we were going in with genetics and prenatal at that time and there was a very helpful Medical Officer of Health, Robin Bolton, that was out of the Public Health unit, and he got on board and felt well, let's be in neutral territory and put ourselves in the Public Health unit. And they selected a Public Health nurse by the name of Pat Forster who was our link and she was sort of, and I am not sure whether she was ready to retire but she was ready to take it on and so she did it for about a year or so and then handed it over to Louise Carriere; she was quite a dynamo and so she became the local nurse to run it and it just bit by bit by bit, and with all of the geneticists, we used to go two of us, and we were always selected two from different centres to go out together so that we would work with different people. And we just really then started getting referrals and giving talks. And every visit we did we gave a talk to a group, everything was organised by the nurses locally, and they were really very, very active locally and it just grew like anything. And then the IODE were very pleased to see it all go and then after a little while they thought now, where else do we go? And I think the second one was Sault Sainte Marie and the third was Thunder Bay followed by North Bay.

PH Following on from that, can I ask: did you use the Ontario outreach programme as your model for North Wales when you came back to Wales?

HH Yes, very much so. And it was like having a second crack at it, because there were things that you knew worked, and things that you know didn't, and so it was very much on that model that things were developed. And this is why you just knew you had to have local services on board, and you knew you had to have good people that could work independently. The people appointed locally really would have to be the key to it all if it was all going to work. Because they had to work independently but also learn on the job because most people would come totally brand new to it so they had to have the ability to learn on the job and develop it basically and not sit back and wait for things to happen from Cardiff.

PH Can I ask: this must have been the first time in Ontario and in North Wales that genetic counsellors had been given a really independent role of organising things as opposed to just helping clinicians?

HH Oh, absolutely. It was interesting because at the same time of course in the North American scene was the birth of the more science-trained academic genetic counsellor - non-nursing trained genetic counsellor - I think with the programme with Kurt Hirschhorn at Sarah Laurence. And so at the time when - now I am not quite sure when Loren started her programme in Manchester - but certainly at the time we were starting most of the people that you would want in this kind of role had to be people who had had clinical experience and knew the medical system. So really they needed to be from a nursing background because they knew how the system worked. So to have someone who hadn't had - there hadn't been the training of genetic counsellors - so that someone you had from a science background who hadn't even been through that training - it really had to be nursing.

PH In Ontario, in your programme there, were there any difficulties in terms of clinicians accepting genetic counsellors? These were in fairly isolated places. How did that work out?

HH You probably need to speak with the people themselves but from my perspective it seemed to work out really well. Now the first person that was picked by Robin Bolton was a woman, Pat Forster, who was a nurse. And also it probably was relevant that she was married to one of the local GPs and so she had a lot of links into the GPs and the system. And you then had to go up and you just had to educate, and this must have been the experience of most people in genetics. You just have to educate. People just didn't know, "What do you do?" This is the standard issue - has always been - and still is, to a certain degree. And so you just had to combine it with this group, that group, and of course the GPs, the hospital consultants, but certainly the GPs, these were key people in that you had to give talks, give lectures, be available. And then, as the nurses got more confident, and knew the areas they were dealing with, then they took on this role in an independent fashion and would be doing it to the nursing people, to the public health who were going into people's homes, were dealing with families with chronic disabilities, so you just had to do it step by step. It was literally - the model I had in my mind - you set up a corner store and you give a product and if you do it well the word will go and the people will come, and just let it happen. You don't have to go out on a big mission, you have to be very careful because you are in this tertiary, funny specialty, you are overlapping on everybody's patch, and the thing to do is you just have to give help when needed and you do NOT just go in and take over. That was the key thing. You are there, and let them just use you, and if it works they'll come to meet you. And don't get into a panic if there's no referrals for a while. But it never was, they just grew and grew, it just happened. So you didn't have to worry about that particularly.

PH Was Ontario the model for other parts of Canada, do you think, and maybe even parts of the United States developing something similar?

HH It might well be, because things were sort of Yes, I would imagine it would. I don't know how many. Some people would come, and we would talk at meetings and that sort of thing, and a few people would come and actually see how it worked and all the rest of it. So I am not sure how much of a model, or if people did it, because it was very difficult at that time to think of any other way of doing it, quite frankly. It seemed to me to be the obvious way of doing it.

PH I know that in the United States at one point there were quite a lot of problems in terms of relations between genetic counsellors and clinical geneticists. Partly, I think, because of the finance models of reimbursement. I sensed that there was quite a lot of aggravation that I'd never experienced in Britain and I sensed perhaps didn't happen in Canada. Did you see anything like that at all?

HH No, not during the time I was there. Obviously I have been away from Canada for a long time. It's then in Canada as well, through Cheryl Schumann, she started her own programme in Canada. She was a graduate of Sarah Laurence and actually was employed in our prenatal service during the time I was in Toronto. She came to work in the prenatal service and she was the first one that we had experienced who was from this model. And again she was a very able person and that could integrate and was very good. And so then she evolved, she started her own genetic counselling programme in Toronto. So in the Ontario system, because you've got a nationalised health system like you've got in this country, people worked in the hospital system under the auspices of the medical system there. Things have evolved there with the more medical model of genetics and a lot of this has happened since I left Canada because it was getting to be a critical mass really in the mid eighties of clinicians because most of us were salaried in the hospitals and with the outreach programme, for example, the expenses were just being paid and there was a fee that was paid that actually went back into our base department. So we didn't at that time run into any financial difficulties. Things have evolved and there's been a lot of stuff that has happened since, I know in Ontario and the different provinces, of how genetics has been reimbursed through their various healthcare systems. But at the time I was there we were still relatively few and we were all salaried in the various hospitals.

I would like to mention my role in the development of the formal introduction of psychological services into the practice of genetics. From the beginning when I started in genetics in the early 70's, I felt that my greatest challenge was in managing the psychological problems faced by the families that I saw in clinic. How to talk to them. I could always learn and find out about the genetic questions but managing families required a lot more than just imparting risk figures. This was the time when prenatal diagnosis was first introduced and Noreen, the prenatal diagnosis nurse Betty Youson and I used to agonise over this aspect. This deficiency was highlighted when Jo-Anne Finegan joined the Dept in Toronto (she was then doing her PhD on the development of infants who had undergone prenatal diagnosis) and she started to interact with the clinical staff, first informally and then on a more formal basis when she introduced the concept of psychological supervision to the practice of genetic counselling and made herself available for this purpose. When I came to Cardiff, I found that this type of formal supervision as an integral part of genetic practice did not exist (I'm not aware that it featured anywhere in the UK) so I made contact with the Family therapy unit which led to the involvement of first Mike Shooter, then Eddie Street followed by Christine Evans. I'm glad to say that this is now regarded as a standard requirement in the training of clinical geneticists and counsellors.

PH Helen, what year was it you came back from Canada to Britain?

HH 1986 and I started in - the clinics in the North got going in about '87. There was a bit of a delay - deliberately - because that's the way I work! There was a lot of agitation because "where is she?" and "when is she starting?" and all the rest of it.

PH I remember that.

HH Again, I just knew that because it is so important that you, you know, if you mess up at the beginning, then that would be the model. 'Oh well, we knew this wouldn't work and it was a bit crazy'. So you had to have the people on board and it was going to start in the way that was - this is again from my experiences in Canada - I knew if you did it otherwise you'd be starting on the wrong foot. So I was in a very fortunate position of yes, I was a new kid on the block, but I had done the job, and also I got away with a lot of stuff, although I was Welsh and from Wales and should know the system, I could go in a rather "Well, forgive me for being so naïve but I have been away" and I could ask questions that two years later I wouldn't ask because you should have known by then and you would have looked bad if you asked them. But by asking them upfront, just for a year or so, you could get away with things that were really - the number of questions I asked that stopped people in their tracks and quite a few, actually, were quite amusing because people hadn't - well, I think you would be aware that coming to the job in the first place, I don't think anybody had done what I had done, almost negotiating my corner, and thank goodness you were very supportive and helpful. But I also knew that if I didn't have it it wouldn't work and because I did have other options and I could have stayed put, although the timing for Cardiff came at the right time for me because of the various transitions happening in Toronto as well, so the timing was right for me, but the whole business of negotiating all of that was something that, other than yourself, most other people didn't know what I was about and didn't know quite how to deal with me. And I remember going up to the then South Glamorgan offices - especially the business for example of knowing that I had to rent a place. Simple things like that. But if you put me in a hotel for a week at a time I would be so fed up with that that it wasn't going to work. So just getting all of that cleared at the beginning, so that you wouldn't have to deal with it afterwards.

PH I remember that. I think the fact that convinced them was that you calculated it would cost a lot more to keep you in a hotel than to have your own bed.

HH Exactly, exactly! And it was obvious, you know, but you had to point that out.

PH Coming back to the situation in the UK, and UK dysmorphology, I have talked with Dian Donnai, but of course I missed Robin Winter, but what are your recollections of the early dysmorphology scene in this country?

HH Well, it was very interesting and, again, due to yourself. You invited me to - you had the Gregynog course, didn't you? - and you invited me over for that. And that was my first introduction to quite a number of people in the Genetics scene in the UK. And it was from then that I started - there was a couple of meetings then that I came to the Clinical Genetics Society, because we had discussed a bit about Cardiff, and so I began to get to know people in the clinical genetics scene. It was different and I think actually it's funny. It was more in other specialties in medicine but it permeated a bit into Genetics. I had come from a much freer, less hierarchical, North American/ Canadian system. If you remember, I had been back for a year in Edinburgh doing this register and I would go to the Paediatric meetings and if I spouted up and asked an obvious question everybody would just turn around and "What is this woman from Genetics? What does she know about Paeds?" almost and "Why is she asking that question?" And again you had to be careful. You couldn't suggest or say anything, you just had to ask the question in the hope that things would make sense to somebody. So that was interesting and, if I didn't have my experience of North America, I would have found it - I probably would have tended to revert to type of the British system. But because I had now grown in confidence, if you wish, you could actually challenge these people and just forget all this "Yes sir, yes sir, three bags full, sir " kind of attitude that was there. So there was still an element of that in Genetics - probably less in Genetics than it was in the other specialties - because it just seemed to be more of an egalitarian crowd. So you had to deal

with that, to begin with, that everybody had to know their place, you know. But there was a crowd, of course, like Di, Robin, John Burn, those were the people at that time that were sort of my era, that were very, very able and pretty assertive and were beginning to breach these conventions, you know, you've probably got a much better view of that than I do. So I remember all that going on and then I came in and by this time I had come over to one of the clinical genetics meetings. It was held in Manchester and for the first time I met Di and she was very progressive in ideas and they had, I think, already established their links with Robin and her and started with Michael Baraitser at Great Ormond St and the dysmorphology get-togethers. And the genesis then of the Manchester meeting, which Di invited me to. I think for the first one I was still in Canada. I can't quite remember. But it was all happening at that time. So really, when I came back, I had already, through Di in particular, I just felt very comfortable in the dysmorphology area, there just was a slot and, of course, we had had similar get-togethers in Ontario between the various centres, where we would get together with - and this again had come from the clinics because we would meet different people from different centres. And there was what they called the Great Lakes Chromosome Conference. There were also links with New England and Vermont, and Eugene Hoyme and John Graham- they were then in Vermont so already links had been established - and of course the David Smith meeting. And then Di actually - I think it was the link to get Di into the David Smith meeting, which was in Santa Fe, New Mexico (whichever year that was) and I think that was again before I came back, it was around '84, '85 or something like that. So that's really when the links were made between the dysmorphology here and Di was the key to that because she was then going over to some of the American meetings and the Canadian meetings, and so on.

PH Helen, we have spent a good bit of time talking and one could go on more or less for ever. But am I right, first of all - well, I know I am right - that you have kept your links with Canada culturally really ever since you left?

HH Yes, I have, because obviously there was the Canadian College of Medical Genetics, which was again the genesis of that, which was a relatively small group at the beginning of about thirty or forty people, maybe. And so again, actually, my links were in particular because that was where the clinical links were because other than Noreen, at the time, there weren't any clinical links actually in Toronto. And then as Fellows got trained and everything sort of grew, I linked with Alastair Hunter, who was then in Ottawa and Michael Partington was in Kingston, and people in London - Ron Davidson in McMaster and Hubert and Howard in London and then more and more people came on board. So when I came back to Cardiff in '86 I still would go to some of the Canadian meetings and also some of the American Society meetings. Maybe not every year but - I don't know, it depends where it was being held - and all the rest of it and if there was something quite interesting. So then I maintained the links with people over the years and because again in the specialty, certainly from that time, there was a relatively small group so it was quite easy to maintain links with people in different centres. And then Judy Hall moved to Vancouver, so she was into the Canadian scene as well and obviously very much on the dysmorphology scene and added to the Canadian dysmorphology scene. So over the years I have kept links with them.

PH Do you feel what you might call reasonably settled now in terms of having Cardiff as a base and frequent visits to North Wales and Canada and everywhere else?

HH I think it's in my nature, because maybe this is where the travelling clinic suited me because I have been peripatetic between North and South. Then, once I retired and had friends in Canada, I started going out there to visit which is - well, no ideas are all good or all bad but then I decided that I had rented a couple of times there and I bought this condo in Toronto so I've now been splitting my time and when people say well, where do you call home, it's a very good question because I am evenly split between North and South Wales, so that's my circuit

between North and South Wales, which is almost as far as Canada. It's still not easy travelling to do that and even if you get the train or even the air service then you need a car so travelling North and South is almost as complicated as travelling to Canada. So travelling doesn't bother me at all, obviously. So at the moment - I have never planned my life, you know, I plan for about a year or two, so for the next year or two do I plan to continue doing this, the answer's yes. But, who knows?

PH Helen, I am going to finish it there, unless there's any very special things you want to bring in before we finish? There are lots of things that we could have gone over.

HH Yes, I know. If there is anything particular that comes to me that I think might be of relevance I can get back to you, Peter. I think we have covered most of the main bits. I think I was - you don't realise until you look back, well you do actually at one level, that there's all this transition and changes that have happened, that it's just been amazing actually in the course of one's professional life and it just carries on, carries on.

PH Helen, thank you very much indeed.