

Caroline Berry



Personal Details

Name	(Anne) Caroline Berry
Dates	Born 1937
Place of Birth	UK
Main work places	London
Principal field of work	Clinical Genetics
Short biography	See below

Interview

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Personal Scientific Records

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Biography

Anne Caroline Berry (b.1937) qualified in medicine from the Middlesex Hospital London in 1961. After internships and a research post she took time out to have three children. During this time she undertook a PhD on genetic polymorphisms in the human skull and taught in a local school. In 1974 she joined Paul Polani's Paediatric Research Unit at Guys Hospital London, as clinical medical officer. She became senior registrar in that department in 1976 and consultant clinical geneticist at Guys hospital in 1979. She has contributed various publications on clinical genetics while her book *Rites of Life* (1987) covers ethical aspects.

INTERVIEW WITH DR CAROLINE BERRY, 14 OCTOBER 2004

PSH. It's Thursday 14 October and I am talking with Dr Caroline Berry at the Linnean Society in London. Caroline can we begin by asking you, how did you come to meet Paul Polani and start at Guy's [Hospital]?

CB. Well it was really through Sam [Sam Berry, her husband], because Sam knew all the genetics people in London and elsewhere and when I had children I took time out of medicine, but in order to keep my finger in the pie I did a PhD in Genetics and also taught at a local school, and so by the time the children were 9, 10, 11, I thought it was perhaps time to think about getting back into medicine, and at that stage there were very few medics with a PhD in genetics.

PSH. Can you remind me, what was your PhD on?

CB. Non-metrical variants in the human skull.

PSH. And was that done at the Galton like Sam?

CB. Yes, Hans Grüneberg was my supervisor.

PSH. I hadn't realised. So he was both your supervisor and Sam's supervisor.

PSH. Am I allowed to ask you, was that where you met?

CB. No. We met actually when Sam was at the Galton and I was a medical student at the Middlesex, and we both went to the same church, so that's where we actually met.

PSH. Right, so you did a PhD with Grüneberg too. In that case I must go back on the chronology a little bit by just by asking, what was Grüneberg like as a person to work with?

CB. Well, I was working from home. I did it over I think 7 years. It involved going to various nice places such as Iceland and Norway, to look at crania, and I'd see Hans not very often and I remember once I was late for our appointed meeting and so he said, as I was a bit late he was now doing something else and I could just wait.

PSH. Yes, the other people I have spoken with, for instance I was just a week or two ago with Tony Searle. He described Grüneberg as very pedantic.

CB. Very pedantic, yes.

PSH. I mean, Germanic would perhaps not be an appropriate sort of thing to say, but a traditional kind of rather rigid German attitude, which one associates with between-the-wars German academic life.

CB. I mean Sam knew him much more, and found that side of him quite difficult to live with.

PSH. So that work, was that looking at skulls in the museum or was it with wild mice?

CB. Well some we actually unearthed from a burial; you went to Shetland?

PSH. I did indeed.

CB Yes at the St Ninian's

PSH. Oh yes.

CB. We dug up the skulls at St Ninian's. I feel, looking back, it wasn't really a very nice thing to do.

PSH. When you say you dug up the skulls, was this the human skulls or the mouse skulls?

CB. I did all humans, you see. Sam did the mice and I did the humans.

PSH. I got the wrong end of the stick. I thought you were doing the mouse craniums.

CB. Oh no no no. I did the humans. It was all human.

PSH. Right. You know I had forgotten about St Ninian's. You probably wouldn't be allowed to do that now would you, wouldn't get through an ethical committee or anything would it?

CB And we stacked them all up somebody's barn. You know, thinking back I wonder what they thought.

PSH. Where did they end up?

CB. I have a feeling some of them went to the British Museum.

PSH. These were all the sorts of saints and you know, whoever happened to be there?

CB. Yes.

PSH. So, really this was a sort of classical anthropometric type of work.

CB. Yes and Don Brothwell was my external examiner. He was a straight anthropologist.

PSH. So you were really doing that part time, during when the children were young?

CB. Yes, I had children and I was teaching.

PSH. So what year was it you actually started at Guy's.

CB. I meant to check before I came. I think it was '74 but it could have been '75. I can easily let you know that. Would you like me to?

PSH. I don't think it matters very much, but of course the thing that I remember, am I right, I think I was on your appointment committee?

CB. No that was my consultant appointment. That was quite a bit later, yes.

PSH. Ah that was later. So what did you start as?

CB. Well you see, when I was thinking where do I go from here? I went to see Cedric Carter, who said "Oh 35. Too old to do anything". That was Cedric.

PSH. That's not very encouraging really.

CB. That was the take-home message. So I then applied for a cytogenetics job with Michael, was it Michael Day at St Thomas's?

PSH. I don't know.

CB. Anyway, fortunately I didn't get that, because I would have made a hopeless cytogeneticist, and then Sam kept saying you ought to go and talk to Paul Polani. So eventually I did go and talk to Paul Polani and he said "Oh well, we do need a clinical officer. Just someone to do the clinics".

PSH. Was there actually a clinic to do or was that started by you?

CB. No, there was an American chap called Jack Donald Singer.

PSH. Oh I remember him.

CB. Well I joined Jack, feeling very green and ignorant because I had actually been out of clinical medicine for quite a number of years, but it didn't take very long for me to rub along with Jack and think, oh well, think I can just about keep my end up here.

PSH. What was your impression of Paul Polani at that time?

CB. When I went to visit the unit, which at that stage was in Keats' house, a sort of private department at Guys, he was a great enthusiast. I remember he showed me around the department and it was awfully interesting and exciting and he said "here we breathe genetics", and we did.

PSH. He still is an enthusiast isn't he?

CB. Yes yes.

PSH. It makes such a difference. So he . . .

CB. So we agreed we would give it a go and we were both adults and if it didn't work, it didn't work and we'd just say it hasn't worked. Because it was a bit of a gamble from his point of view.

PSH. Yes.

CB. So that's how it was. There was no appointments committee, there was nothing. It was just a private arrangement.

PSH. And what kind of patients were referred, back then?

CB. Well, quite a lot of people with Turner's syndrome and people with consanguinity and of course, what was happening just then, which was really why they needed somebody, was the whole alphafetoprotein was just taking off, so we saw a lot of people who had a history of neural tube defect.

PSH. Had prenatal diagnosis got going at Guy's?

CB. It had just got started, yes.

PSH. It must have been really just at the very earliest stages.

CB. Yes, alphafetoprotein was just being used and so quite a lot of the people we saw came for amniocentesis counselling.

PSH. Was Stuart Campbell there then?

CB. Stuart Campbell was sort of lurking in the wings just then and they were just starting to get 'Wow, look ultrasound. It's anencephalic. You can see there's no cranium.'

PSH. Because there must have been quite an interest from obstetrics, I guess, from an early stage perhaps?

CB. Yes, we had a chap called Tim Coltart, a sort of interested obstetrician and they did the amniocentesis in the department and so it was quite a team effort, but Stuart Campbell was at King's of course, so he was separate.

PSH. Of course, I was forgetting that there really wasn't a link in those days.

CB. No, so Stuart was sort of down the road producing these pictures and in the early days the amniocenteses were done blind.

PSH. Yes.

CB. Because the ultrasound department was separate, so the woman would go and have her scan and then . . .

PSH. And go half way across London

CB. I think they were having the scans done in Guys by then, but not in the obstetric department. It was probably in X-ray or something like that.

PSH. One of the things when I was talking with Paul Polani, he felt very proud of was, that at quite an early stage following on from his research, he had managed to get funds from the Department of Health to develop services, quite really at a pretty early on stage. So were you funded as part of research, or did you come out of a service budget? Probably it wasn't clear.

CB. I think Jack probably was on the service budget and I was probably on a research budget; I was only working part-time at first.

PSH. So then they made you a consultant in

CB. Oh that's long, long way ahead, before

PSH. Tell me what happened.

CB. We were in Cameron house and then Jack and I moved into the new department and then Jack was the registrar, Jack left and then the real crunch thing was, did I go full time and become that post, and I was a registrar for a long time you know.

PSH. I had forgotten that and I always imagined that you had a senior appointment before they actually had any training post. So I suppose you must have been one of the first of the kind of registrar, senior registrars?

CB. That kind of thing yes.

PSH. Along with people like Ian Young and others.

CB. Yes

PSH. Right. At that time, how did the different parts of the Guy's unit inter-relate, because it was really the biggest of its kind, wasn't it, certainly in London and possibly outside Edinburgh, but it was very well planned and established.

CB. And it interacted very well, we had the cytogenetics lab, which of course the clinicians worked very closely with.

PSH. Who was running that at that point?

CB. Michael Daker and Sue Blunt did all the amniotic fluid tissue culture.

PSH. So already there was prenatal as well as postnatal cytogenetics built into the unit.

CB. That was going on before I started.

PSH. Yes.

CB. Because this was one of the problems with the move you know, amniotic fluid cell cultures, if you breathed on it they failed in those days.

PSH. And who else was there?

CB. Well there was Philip Benson and Tony Fensom beavering away in biochemistry.

PSH. So were they actually in the biochemistry department, or were they part of genetics?

CB. No they were part of the unit.

PSH. Yes, that's what I thought.

CB. Once we moved out of Cameron House we moved into these two floors of beautiful purpose built buildings.

PSH. Wonderful.

CB. Yes, with Matteo [Adinolfi] beavering away on immunology, Philip Benson and Tony Fensom doing the inborn errors side, cytogenetics, Mary Sellar focussing on neural tube defects and Francesco [Gianelli] who was at that stage doing chromosome breakage syndromes.

PSH. That was before he developed the haemophilia work.

CB. Yes. Just to follow Francesco, when molecular genetics started to appear, of course we had no molecular genetics and clearly that was the way the world was going to go, so Francesco, very bravely I think, was sent to Oxford for either a year or two years, I don't know how he got there from Croydon, to become a molecular geneticist, which he duly did. Commendable. And that was all in Paul's day.

PSH. I mean, looking back on it, it seems very, very far sighted that all the main elements really were in place in terms of clinical genetics, biochemical genetics, cytogenetics and good basic research. That really must have been Paul's vision.

CB. And that was the strength, that was why it was a great department and of course everybody spoke to each other and had seminars and things, so that you knew what was going on in other people's labs.

PSH. To what extent was Paul himself involved in the clinical service for genetic counselling? Was he at all involved?

CB. Oh yes, he used to do a clinic on a Tuesday morning and he would see two or three people and save up special ones, or some of them were people who had been particularly referred to him and he would come with his secretary to take shorthand notes and I would be there to talk to the patients afterwards, and I mean he was very research orientated, but also he was very good clinically and he was kind to the patients. I can tell you a little story about clinical acumen if you would like it.

PSH. I would.

CB. Well one of his specialties was what today we call Noonan's but which he always insisted on calling Bonnevie-Ullrich syndrome, because that's the European name, and so this family was referred from the Brompton where one child had a heart defect and one child I think had died with a heart defect or in infancy, or did die soon after this, I mean it was a serious congenital heart defect. And it was thought they had familial Noonan's or familial Bonnevie-Ulrich and then the mother was there and rather to my surprise Paul said to the mother "would you mind taking off your clothes?" so she did and she was covered in lentigenes and he had picked up that she was a bit deaf, so that was very instructive.

PSH. One of the things that I didn't realise until I went and interviewed Paul, he spent virtually the entire war single-handed, running the Evelina Children's Hospital

CB. Yes, in the Evelina, yes.

PSH. And done all the surgery there, so he did have a wonderful clinical background.

CB. That's right, and I mean he was very good clinically.

PSH. So

CB. Can I just . . . , there's one person you have missed out, who was really running the clinic, or running a separate clinic right from the start and that was John Fraser Roberts.

PSH. You're absolutely right, because again it was something I learnt when I saw Paul. I had always imagined that John Fraser Roberts had stayed at Great Ormond Street, but in fact when he retired he moved across to Guy's, didn't he.

CB. Paul sort of snatched him I think. Paul . . .

PSH. That's what I gather.

CB. Paul was quite, you know, he didn't let the grass grow under his feet and I think he realised we needed a clinician and roped him in and he used to do these clinics, can't remember now whether it was once a week or once a month, at which people with the usual sort of things, talipes and things, and his secretary would again, I mean it was slightly run by the secretary.

PSH. I mean John Fraser Roberts must have been, well he must have been in his 70s by then.

CB. He was quite elderly and he had nice little mannerisms that I used to say to myself when I was going on an aeroplane, "the outlook is really very good".

PSH. Because I always think of John Fraser Roberts alongside perhaps the very first people who gave genetic counselling, who weren't really clinicians in quite the same way.

CB. Sheldon Reed.

PSH. Exactly, I think of him

CB. He's just died.

PSH. I think of him as a bit of an equivalent. I think of him as more of a person involved in genetic counselling rather than a clinical geneticist.

CB. Yes, he was not really a clinical geneticist. He did medicine because he didn't think anyone would take any notice of him if he wasn't medically qualified.

PSH. Yes. And then eventually he did a few clinics down in Bristol again, didn't he?

CB. Did he? I don't know.

PSH. I believe so.

CB. I felt he went on a little bit long, really.

PSH. That's always possible to do, I think. Yes, I'm glad you mentioned him. So really, in terms of people involved in genetic counselling, there really were several of you from the beginning.

CB,. Yes that's right. I mean there was Jack and Fraser Roberts and I and Paul all doing slightly different, I mean the prenatal stuff was all seen by John Singer and I, and then Fraser Roberts had his own referrals and his own secretary, so that was a bit separate, but I learnt a lot from going to his clinic, just seeing the people.

PSH. Because actually that's very different from a situation where a person is absolutely single-handed and has nobody else to talk to about clinical or counselling problems.

CB. Well that's right, which a number of early appointed consultants were very much. Chris Garrett was all on her own down in Exeter for a long time.

PSH. Yes. So now we've got just about to the point where they, probably rather long overdue, made you a consultant, and that would have been about '78 or something would it?

CB. I should have checked. No I would think it was later than that. There was no need you see, Paul ran the unit. I was quite happy to run it, to do what I did.

PSH. There weren't all the regulations.

CB. There weren't all the regulations.

PSH. No. So when was it then that you had other clinical staff coming in to support you, apart from the folk who had just been around for a long time like John Fraser Roberts?

CB. Well Chris Garrett was the first true senior registrar appointed and then Ann Child was around. She came as a part-time person quite early on.

PSH. Yes. And then when was it you had a second established consultant post, quite late on I guess,

CB. Quite late on,

PSH. I am trying to remember who that might be.

CB. Well, I think it was Shirley [Hodgson] .

PSH. It must have been. Had she been a trainee with you?

CB. She had been a trainee and then she had got a consultant post in Cambridge and commuted from Cambridge and was quite glad to come back.

PSH. And would I be right, by that time, Martin Bobrow had taken over as Director of the Unit from Paul Polani.

CB. Yes I think so.

PSH. Tell me a bit about how the regional side developed. I mean when you started, presumably people came along to Guy's but there wasn't anything anywhere else.

CB. Well, we provided right from the early days a chromosome service for the region, so one of the things that happened was that people would ring in because they wanted to check a baby's chromosomes, and because the culture was so difficult then, we used to send out special bottles. They couldn't send them in, we had to send them out. It was all actually quite tightly controlled.

PSH. And when did you first start doing clinics in other places?

CB. Regional clinics? Quite late on. I remember the first clinic I did elsewhere, and that was in Brighton and I was certainly a consultant by then.

PSH. So probably in the mid eighties.

CB. Mid eighties I should think.

PSH. And then

CB. I mean I could check these dates in my diaries going back.

PSH. You have your diaries going back, that's a wonderful thing!

CB. Just, you know, it will say Brighton clinic or something.

PSH. Yes. And where came next after Brighton? Well don't worry about the order perhaps, but as an outsider I'm trying to get an idea of how it evolved, so which were the other centres that sort of gradually started?

CB. Well, we had Hastings, Folkestone, Maidstone was a later one and Lewisham was a later one.

PSH. How many were there in all by the time you finished.

CB. Well, by the time I finished there were probably about 10. We'd share them out.

PSH. So in some ways not unlike our own set-up in Wales.

CB. Yes that's right.

PSH. Now did you have genetic nurses or genetic counsellors from an early stage?

CB. Yes, we appointed Teresa Barby and she must have been one of the first genetic nurses in . . .

PSH. So did she go to these regional clinics or did she stay back at base.

CB. No. She did a lot of prenatal counselling, because at one time I was seeing half a dozen prenatal people and then three ordinary people.

PSH. Did it take you a long time to persuade the obstetricians that they really needed to do some of the counselling themselves?

CB. Oh, we never let them do it. We didn't trust them. No, we insisted that they should be seen in our department.

PSH. Right. What were the other main changes as you saw it over the past 20 years?

CB. Well we always maintained very much a regional flavour, because we would always make personal contact with obstetricians with difficult amniocentesis results, so I would know all the obstetricians in the region on christian name terms. And the paediatricians, again we had quite good links, because again they would send children with syndromes or ring about a baby, did we have any ideas. So we did have telephone links right from early on and we made a lot of effort for those, because that seemed to be, well for one thing it was probably where the money was, you know unless we were providing a regional service we couldn't ask for regional money. I mean I don't think our motive wasn't really financial. It just seemed to be what was needed.

PSH. Do you remember when it was at all, when the funding of the service became regional rather than just Guy's.

CB. Oh right from early days, I remember going and seeing a nice man who has now died who became, Stuart Horner I think it was. He was then at the regional offices in Croydon. And that was really quite early on because I remember he said, oh I had had to do a piece on television, on the evening thing, about amniocentesis because this was all new and I had only just, we were in the new building, I had probably been around two years say, so that pinpoints when Paul and I went to see this chap and said we must have funding for this.

PSH. And from my talks with Paul, he gave me the feeling that they were really very receptive.

CB. Well that's right, he was very friendly, Stuart Horner.

PSH. I have never been quite sure whether that was because you were very fortunate; it must have owed a lot to Paul's persuasive skills I think.

CB. Yes.

PSH. And his reputation. Because I think, if one looks across to many regions, they had such a battle to get things going at all.

CB. I mean we had a constant struggle and it got worse of course, because of, you know, under the Maggie years . . .

PSH. Well the internal market could have killed genetics completely. I think it's a major miracle we survived.

CB. So all those years were very difficult financially and also I was more aware of them by then, because I was then having to

PSH. You were running the service then.

CB. Yes, whereas in the early days Paul was the one who . . .

PSH. One of the things that actually has impressed me, still impresses me about genetic services, is that on the whole people have had a very good tradition of hanging together and supporting each other, and this has paid off when times have been bad, and I guess it's always seemed to me that Guys and south east Thames was a good example of people working closely together and not kind of getting split up into factions.

CB. The PRU unit worked well together and we didn't have anyone, I suppose the Stuart Campbells were slightly, Jack went to Stuart Campbell when he left.

PSH. Did he, right.

CB. And I think Stuart thought he was getting a good thing.

PSH. So by the time you finished then, just remind me what year was it you did retire?

CB. Oh, I know when I retired. I retired in 1997.

PSH. 1997, so by then you'd got very strong molecular genetics.

CB. Yes, brilliant molecular genetics.

PSH. Am I right that the haemophilia had become closely linked through Francesco Gianelli and . .

CB. Francesco had this register. It was a fairly stand-alone thing. It didn't really involve the clinical team. We didn't see haemophilia patients, it was more a thing where people were registered I think, so there was a kind of bank or knowledge of all the mutations.

PSH. So by the time you finished, how many were you at consultant level?

CB. Well, there was Frances Flinter and Shela Mohammed, I think that was the consultants, no more, and I think we only had the one senior registrar or specialist registrar, but we often had other people come as trainees for one reason or another, they were seconded. The good thing now is that the registrars rotate, because that was always something we wanted to do, because we were weak in dysmorphology.

PSH. Yes, but then with Great Ormond Street in the same city . . .

CB. Yes, but you see for our peripheral clinics I never thought, because the paediatricians actually often had children that they wanted a dysmorphology diagnosis for and I wasn't particularly good at that. Chris Garrett was good, and again I felt that for the trainees they really needed to go to G.O.S., whereas we had excellent cytogenetics, but at that stage that kind of interaction for various reasons wasn't possible. But the good thing is it is now.

PSH. Are there any other sort of things about the Guys genetics set-up that I haven't touched on that you feel merit putting down, because . . .

CB. Well we used to work closely with the paediatric neurologists. You knew Roger Robinson?

PSH. Roger Robinson, I did indeed.

C.B. and Brian Neville, so we would go on their ward rounds and that was a good link, and then of course later Shirley developed good links with the oncology people. We also had good links with Richard Hughes and Ros Fermer with the neurofibromatosis and we did have, the relationships with Kings were kind of hot and cold. At one time we did have regular meetings to discuss what we were each doing and contributing things and those were healthy, otherwise it became very easy for it to become them and us.

PSH. Yes. It's been an extraordinarily exciting period to work in genetics. Have you ever had any regrets or wishes that you had chosen anything else?

CB. No no. I used to say that people needed to change their job every 7 years so that they didn't get stale, but with genetics the job changed so much there is no need to change, the job changed.

PSH. Yes, and you had to change with it.

CB. Yes. It's amazing, starting with the Fraser Roberts days, you know one chance in 25, really a very good outlook. That was about all. That was it you see.

PSH. All you could do. It is amazing isn't it.

CB. And now Duchenne, well you know, Huntington's, do you really want to know, that kind of thing. Entirely different. Really exciting.

PSH. One thing just maybe to finish with, you've always had a strong interest in the ethical issues. Do you think we've coped well as a profession in genetics with all these ethical issues that we have come up against?

CB. I have always maintained that people need to meet the clinical geneticists that come to clinical genetics meetings, and realise that the clinical geneticists are very ethically aware, because there's sometimes from outside, people think, oh they are gung ho, rushing round telling everyone they mustn't have children with disablements and things. But no, I mean, then all the business with the Huntington's and things, you've got all that, not sorted, but you raised the flag, so I think the genetics community has been aware and ahead of the game on the ethical issues and seen what was coming and thought about it before it all got too out of control. Now whether that is continuing I . . .

PSH. Yes, whether we can transfer it to all the wider groups who are having to handle it

CB. This is the thing.

PSH. That's the challenge isn't it?

CB. Because we were such an in group. Everybody knew each other by name, and again that was the other good thing, oh I'll ring so and so and see what he thinks.

PSH. I think, looking back, in the future, people may well look on this time as a wonderful time because we were such a closely knit community.

CB. Just to go back right to the beginning, one of the things I remember, which slightly got me into clinical genetics, was I went to the first meeting of the Clinical Genetics Society, I'm not quite sure why, and thought this is so boring, all the diseases are so rare. All this time the Lancet was full of

squashed spider pictures of Edwards syndrome and things and then I always used to for some reason look at the adverts for jobs and I remember seeing the first consultant clinical genetics post advertised, and that was in Cambridge.

PSH. In Cambridge?

CB. Yes Clare Davison.

PSH. Good heavens.

CB. You would be able to trace the date of that, but I remember thinking wow, so there's going to be consultant posts in clinical genetics, so it is going to be a viable profession, you know professional. So that was, funny how you remember little things. I just remember seeing that advert.

PSH. And now it's grown to be quite big.

CB. Yes that's right. Now we have our own little section. That was the first.

PSH. Caroline, thank you very much. I am going to stop the recording there. It is very good to talk to you. Thank you.