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APPENDIX A

TRANSCRIPT 1

c: Well we haven't spoken, but I wrote to you after your letter....

5 fp: Oh it was you that wrote the letter....!

c: Well yes, you may not remember my name but I'm aware of what happened

10 fp: Yes...

c: I guess you have some sort of specific questions that you want to fire at me

15 fp: Yes....

c: Which is fine....

fp: Yes....

20 c: How have things been since...?

fp: It's the fourth week....

25 c: It's fairly recent, isn't it.....?

fp: The first week was very hard....wasn't it....?

mp: Yes...

30 fp: but then you get used to the idea, don't you....that she's gone or whatever...

mp: Yes...

35 fp: Because it was a shock that she was Down's Syndrome...

c: I think when we wrote you weren't aware of that problem....

40 fp: Yes...

c: ....did Mr Bamford talk to you about that....?

45 fp: Yes. It was him that told us when we went back...

c: Yes...

fp: We just thought it was water on the brain or whatever....

50 c: Yes...

fp: ...and that it had been caused by a virus or something...

mp: ...that's right...

55 fp: ....and when they said Down's Syndrome it has sort of far reaching consequences, doesn't it...Down's Syndrome, for the future and whatever...

mp: ....complete shock ..

60 c: So that was a bit of a shock....

fp: A setback, that was....

65 mp: ...yes....

c: Did Mr Bamford mention the future....I don't know whether you know about the implications...whether you know what Down's Syndrome is or...?

70 fp: Not really....he just said "Would you like to go to Guy's?"

75 c: That's fine....Are you sort of familiar with chromosomes....did you do that in biology or...

fp: We did some...three of one particular one or something...

80 c: That's right....I don't know whether...quite a lot of people nowadays have read articles about genetics and know as much as I do...! Human beings basically are supposed to have 46 of these things called chromosomes in

85 each cell, with the exception of the sperms, which I'll come back to....

fp: Hmmm

90 c: But the idea is that we inherit chromosomes from your parents..

fp: Right....

95 c: ...you inherit half from your mother and half from your father....

fp: Right....

100 c: And we number the chromosomes....this would be the chromosomes in each cell....

fp: Right....

105 c: So you have a pair of No 1's and a pair of No 2's and genetically they go down in size, and we number those chromosomes as a sort of international code....

110 fp: Right....

115 e: And there are 22 chromosomes in pairs, the 23rd chromosome is that one that tells us our sex, so that you'll have an x chromosome which you have got from your mom and your dad will give you a y chromosome which contains the genes....y's only seem to matter....you and I don't get a y....[difficult to hear]

120 Now what should happen, the idea is that when you come to make eggs and sperm, because if you passed on your whole set of chromosomes to a child they would inherit a double set...

fp: Hmm

125 e: ...which is, you know, twice as many as you actually need...

fp: Right...

130 e: This is a splitting of chromosomes pairs....passing one of each pair into your eggs or sperm...the idea is that when you make eggs you pass one over one [difficult to hear]

135 fp: Right...

e: and obviously the idea is that 23 chromosomes.....[difficult to hear] and that's how it's supposed to work....

140 fp: right....

145 e: It all sounds so simple...but what we know is that the business of splitting chromosomes may sound simple but is actually very complicated and it often goes wrong....for example we know that's how pregnancies begin...how conception occurs....and how miscarriages occur...a large proportion of those chromosomes in some way....

150 fp: Hmmm

e: In other words problems with chromosomes are extremely common but we don't know about them because nature has a habit of sorting out its mistakes...

155 fp: Hmmm

e: So that's how things can go wrong....

160 fp: Hmmm

e: Now what happens with Down's Syndrome is that when...the baby that you lost we know had Down's Syndrome because we looked at the chromosomes...

165 fp: Right...

c: ...and she had an extra chromosome on the y....so in other words she had 47 chromosomes...

170 fp: Right...

c: ...and it seems to be that normal chromosomes seem to need exactly 46...if you have too many, or too few, you get problems, and that extra chromosome was probably there even before she was born...in the sense that it may have been there in one particular sperm or one particular egg....

175

fp: Oh right...

180 c: ...and we know that probably everybody produces eggs and sperms that have the wrong chromosomes

fp: Right...

185 c: But either those are not the ones involved in conception or they're the ones that miscarry, most people are not affected....

190 fp: Right...

c: So in other words there is nothing you could have done...

fp: Yes...

195 c: Absolutely nothing....it was there at the very beginning...and we don't know why these things happen...we don't know why it happens...but as you may have heard it tends to be more common in women as they get older...it's more common in women who are pregnant after about 35, which is why they have these tests in pregnancy called amniocentesis...mainly because it tends to be more common in older mothers - "older" being in this case over about 35....

200

205 fp: Right...

c: ...but we do know that the vast majority of Down's Syndrome babies [not possible to hear]

210

So that was basically what was wrong...basically she had an extra chromosome....

fp: Now the good thing is that we know this is the kind of thing that tends not to reoccur to the same couple....

215

fp: Right....

c: In other words it is usually a one-off event... a genetic accident...

220



fp: Right...

ca: And it very seldom happens to the same couple...

225 mp: ...twice...

ca: And we know that Down's Syndrome is quite a common problem and therefore we know lots and lots of people who have Down's Syndrome babies...and if you look at what happens on their second, third and fourth pregnancy, you very very seldom find a couple who have this problem twice...in other words it's not an inherited thing...it can be confusing because Down's Syndrome is defined as a genetic condition....

235 fp: Yes...

ca: But not all genetic conditions are inherited...it may be that there's something wrong with the genes or the chromosomes....

240 fp: Right...

ca: But not all of them are inherited...and we know for sure that this kind of Down's Syndrome...there is a rarer kind of Down's which is inherited...but this kind of Down's for sure is not inherited...

245 mp: Can we have problems with our chromosomes though, before ....[?] we had a miscarriage as well....

ca: Well...how many...did you just have the one miscarriage....

255 mp: We had one, and then we had....[?]

ca: The problem with miscarriages is that they are so common...

260 mp: Yes...

ca: One pregnancy in every four ends in miscarriage....only some of which will have Down's Syndrome...some of which will have reasons which are not known....basically, having had one miscarriage, and having had a baby, it doesn't mean to say there is something wrong...in fact quite the reverse...it's not usual for us to check the chromosomes for people who've had a baby by what we call the [not possible to hear] because we virtually know....

270 fp: Oh right....

ca: It's something that went wrong very very early on...just after conception or just before...it's not likely to be a problem which is why we don't usually check the chromosomes level....[not possible to hear]

275

fp: The inherited ones...they look different do they...?

280 a: They do look different....I'll just show you the inherited ones...

This is...it looks at first glance as if this baby has two....

285 fp: Right...

a: Actually there is an extra chromosome stuck.. chromosome 14...in other words there are three chromosomes...and that happens to have all these things...that's called

290 translocation Down's Syndrome...

fp: Right...

a: And what can happen is that that 14th chromosome that's

295 stuck together can be one of the other pairs and they just pass it on with one other 21 and a part....

fp: Oh right...

300 a: ....that is for sure the inherited Down's Syndrome...

fp: Right...

a: But we've looked at your baby's chromosomes and we know for sure that she doesn't have this kind...she has this kind where there are three completely separate chromosomes...we can be absolutely 100 per cent sure about that...

305 fp: Right...

a: ...but this is not...fortunately you can tell the difference...from looking at the baby...

315 fp: Huh-huh...

a: There's no way you can tell...because if you have an extra chromosome there are several things that can happen....

320 fp: Hmm

a: ...but that's why a chromosome test is so important...

325 fp: Right

a: If you don't have it...we can't tell which kind it is...and therefore there's always the worry that it's the inherited kind, but fortunately

330 fp: Right...

c: But fortunately with you, by doing the test, we can know  
 for sure...  
 335 fp: Yes...  
 Somebody said something about the creases in her hands or  
 something that we didn't understand...  
 340 c: Right....do you know people with Down's Syndrome...?  
 fp: No...  
 345 c: Syndrome...the word "syndrome" just means a collection of  
 things together...  
 fp: Right...  
 350 c: And it's called Down's Syndrome because it's Dr Down who  
 was a Doctor a hundred years or so ago who pointed out to  
 people that there were a lot of children and adults who  
 had very similar facial features, all of whom had what  
 was then termed "mental handicap".....  
 355 fp: Right...  
 c: And he basically pointed out that they had very similar  
 features...and it used to be called Mongolism...because  
 360 they had an unusual slant of the eyes rather like the  
 Mongol people...  
 fp: Right...  
 365 c: And there were various other features that they had that  
 meant that facially they were very similar...but it  
 wasn't until a hundred years later when we discovered  
 chromosomes that we realised that there was an actual  
 basis for what he was saying...that all the things he was  
 370 talking about have separate chromosomes....  
 fp: Right...  
 c: And what Dr Bamford may have talked about is that if you  
 375 look at the palms of your hands  
 fp: Yes...  
 c: Most people have creases like these ones that go sort of  
 380 crossways...  
 fp: Right...  
 385 c: What children with Down's Syndrome often have is what we  
 call a single palm...in other words rather than the three  
 creases that we have...three definite....they have one  
 that goes across the palm...

390 fp: Oh...

a: It is very possible that she had those....I only have a report of....so that...yes that's right...she did have a single crease....

395 fp: Oh right...

a: So in other words she had just one crease....now that tends to happen with Down's Syndrome....the confusion is that you can also get it in normal people

400 fp: Oh...

a: If you go up to people in a room, the chances are you'd meet some people who purport to be healthy with a crease like that...

405 fp: Right...

a: In other words it's not diagnostic of Down's Syndrome....but it tends to happen more commonly in Down's Syndrome than in people who don't have Down's Syndrome....

410 fp: Right...

a: ...which is why it's an indicator and not a sure test...

415 fp: Sure...

a: ...and it's a very minor thing, but it's something that you can see...

420 fp: Yes...

a: The other thing that can happen in Down's Syndrome is that the physical thing, very common in Down's Syndrome, babies have some kind of heart problem....you've heard of hole in the heart...?

425 fp: Yes

mp: Yes

430 a: They tend to have those sort of problems which can be very severe

435 fp: Right....

440 a: And it's often one of the reasons why [difficult to hear] what basically happens in chromosomes...is that chromosomes carry the genes or the individual genes which fitted together make the human being, as it were...

445 mp: Yes...

450 c: And we know that for instance...if you're thinking about how was the brain affected...it probably means that there are all sorts of genes involved in making your heart into a normal heart...it's very common for Down's that babies have a problem with their brain...all her problems were related to her heart...that was the root cause of what went wrong...

455 fp: Right...

460 c: In other words if you have a baby who does not have an extra chromosome the chances are that all will be fine....

465 fp: Right....

470 c: Does that help.....

475 fp: Oh yes...  
We were wondering if we were incompatible or something...you know...

480 c: I can understand...I think that's very very natural to feel that...when you've had a baby with problems the memory of it grows...[difficult to hear]

485 fp: Oh yes...  
...I think most people who are young healthy people expect to have babies with no problems, which most people do, but when it goes wrong...

490 fp: There's something else...if I have another baby would you recommend that I have an amniocentesis...

495 c: Having said that it's unlikely to happen again...the real difficulty is we can never say for sure...

500 fp: Right...

c: We don't have crystal balls....

490 fp: Right...

c: We do know that there are occasional couples who are reported as having a second baby....

495 fp: Yes..

c: And what we do in order to say how often it happens is to look at what happens in general terms...and we think the chances of you having another baby like this are about 1 per cent or 1 in 100....

fp: Right...

c: Or 99 good chances to 1 bad...

535 fp: Right...

However...it depends whether you think in terms of percentages or whatever...in other words the chances of you having a second baby with Down's Syndrome are higher than somebody in the general population...

540 fp: Oh right....

c: But...not that higher....in no way would we regard you as a high risk...

545 fp: Oh right....

c: In other words there's a risk everybody carries, however: (1) I say it could happen and (2) I would guess that it won't....

550 fp: Yes...

c: Because of those two things, if you wanted to have a test you would be most welcome...

555 fp: But the thing is I've heard there's a risk of miscarriage....

c: Well that's right...it's not the sort of thing I intended to go into today...

560 fp: Hmm

c: ...but in the future, if you had a pregnancy and wanted a test, that would be available to you

565 c: ...if you wanted to that's a perfectly logical thing to do....

fp: Is it a back of the neck test or something....

570 c: That's called a....the word is Nuchal...and basically all that means is that what they do in this case is that they using a Nuchal scan they measure the thickness in the skin on the back of the neck...it's because in Down's Syndrome it's relatively common for the baby to have that skin...

575 ...the problem with that test is that it is perfectly possible for a normal baby to have an increased skin thickness...

580 fp: right...

And it's perfectly possible for a Down's Syndrome baby to have normal skin thickness...

550 fp: Oh right...

ca: In other words it's one of these indeterminate tests....

555 mp: Bit like.... ?

ca: Exactly....but if you see it, you think "Well that's worrying" but there's no way for sure that you would know from that.... because just like normal people have thick skin....

570 fp: Yes...

ca: And what that scan really is about is that one of the problems is that we always offer tests to people over 35

575 fp: Right...

ca: which has meant that people in your position generally have not been offered tests, therefore this happens without you having had a test...and so the problem is not spotted...

580 fp: Yes...

585 ca: Now that is pretty un-ideal...even though your risk if you're over 35 is greater, there are more people under 35 having babies who are not being screened...we feel this is unsatisfactory so we're trying to develop a way of screening the general population to see whether there is a way of spotting which particular person, irrespective of their age is a higher risk than others and there are various ways you can do that one is a blood test whether they measure the levels of a certain chemical in your blood

590 fp: Right....

600 ca: and it puts the results in a computer along with your age....that's called a Triple Test and there's a Hart's test, depending on where you are and more recently there is a test which is offered at King's

605 fp: Right...

ca: and the more recent one is a scan which is offered at King's and what King's are doing is a research project on how effective it is at picking up

610 fp: Right....

and it seems that it has benefits but it is not a Yes/No

test...

615 fp: Right...

620 c: Unfortunately the only way of having a Yes/No test is to have one of these tests where they take a sample of the fluid from around the baby...an amniocentesis...and there's another test called a CVS test...have you heard of that?

fp: I think so...

625 s: I'll give you some information...

There is an earlier test...amniocentesis as you may not know...works by taking a sample of the fluid surrounding the baby....

630 fp: Right....

s: And usually it's not done until you are about 16 weeks...

635 fp: Right....

s: and it's true it carries a miscarriage risk...about 1 in 150

640 fp: Right...

645 s: And it also means that you are not getting the results until you are about 19 weeks into your pregnancy...but the only way if you want to really know the results is to go through this....that's obviously a major drawback because it's quite late on in the pregnancy....

650 c: The earlier test which is called CVS basically works by taking a sample of the developing foetus, and you can do that after ten and a half to eleven weeks

fp: Yes...

655 mp: Is there any.....with that.....?

660 c: Well, the advantage of that test is that if the worst came to the worst and you wanted a termination you could achieve that and it's obviously physically less stressful than the test later on....the main disadvantage is that miscarriage risk is higher than the other one...it's about 1 in 50....in other words it's about 3 times higher...that's why there's no recommended test...because they all have their drawbacks and the all have advantages...It's a matter of weighing up when you're pregnant....what's most important.....? is getting an earlier result the most important

fp: Yes...



570 fp: and that is by taking....or do I think that 1 in 100 is not really a bad risk...in which case we'll wait for the later results when we're fairly sure things are going to be OK

575 fp: hmmm

c: it's that kind of weighing-up business that you'll need to do...

580 fp: Yes...

c: ...and people do differ....there's not a right or wrong decision...they all give you the same information...it's when they give you the risk.....some people who have had three or four miscarriages may wait....other people who have had a difficult time...like you perhaps...will give anything to know sooner and will have the earlier test it's a very personal decision...

635 mp: Hmmm

590 fp: Yes

595 You can have either test...whatever you want to do...some people because of the worry, choose a third test...there's usually a couple of special scans in the Special Scan Department...they have one at King's and we have something similar here called the Fetal Medicine Unit...

700 fp: Oh yes...

c: ...and both departments offer special detailed scans, looking in depth at the baby, by people who are experienced at these things...and because babies with Down's often have a physical problem....like the heart, or the brain

705 fp: Yes...

710 c: on the thickening at the back of the neck....

fp: Yes...

715 c: Those are the sorts of things that can be looked for on a scan...and the advantage of the scan is that you can have as many as you want...there's no way it can cause miscarriage...and if it did pick up something like heart, because that's more worrying....

720 mp: Yes...

c: ...then you would have to have the amniocentesis done because really....

725 fp: Yes...

c: And if everything looked fine, looked normal, that would really reduce your risk of having a problem....but it wouldn't get rid of it...

730 fp: How do you mean...

c: Well it's late....you are looking for things like...the hole in the heart...that's not really visible until you are about 18 weeks....that's the only drawback to that approach...

740 and the other thing is that even if the baby looked fine and normal, there is still a potential risk because we know that with Down's there is are certain things that have no physical appearance whatsoever, and it's not until a baby is actually born that something is seen to be amiss....

745 fp: Right...

c: and so it would reduce your risks, but it wouldn't abolish them...

750 fp: Right...

c: So there are a number of things you can do.. you won't just be left to get on with things.....if you want a special test organised...that's very possible....

755 mp: Well King's said to go up for a scan at 12 weeks and then 16 weeks...

760 c: That's because they're starting this new scanning business....some people find it helpful to have this....it may not resolve this....and if you felt you wanted a more sure thing then there are other things...

765 fp: So do I just go to the GP and ask.....?

c: The thing to do is as soon as you find you are pregnant is to go to the GP to get the pregnancy confirmed, and ask for the tests, and then your GP will refer you either to King's or Guys....there's no real fundamental difference in the tests you will be offered at the different places

770 fp: Right....

c: Some GPs use King's, some use Guy's...it's all to do with contracts....you've probably heard of changes in the NHS....it's very complicated...

780

fp: Right...

785 ca: But at the end of the day...the bottom line is that the test will be available either here or at King's...

fp: Right...

790 ca: No matter where you go you will still get access to the same tests and the same treatment...and if you were to move to Northumberland or whatever...there's always a centre locally...

fp: Right...

795 ca: CVS is offered at a few special centres because it's a specialised test...King's being the main place...

fp: Right...

800 ca: Whereas amniocentesis is quite a common test...it's done at many local hospitals...

fp: Oh Yes...

805 ca: CVS is specialised and much rarer test...it's much less used....but if you decided you wanted to have that you would be very welcome

810 fp: OK

ca: But your GP will arrange this...it's a big decision if you want to come back and talk in more detail about the pros and cons in more detail, you will be more than welcome.....

815 fp: Thank you....

ca: It's sometimes quite good to talk when you are actually in that position...what may seem best when you are sitting here now....will actually seem different

820 mp: That's right, yes....

ca: May change and if it does well that's quite normal....

825 fp: Thank you....

I'm a bit worried about the future....

830 mp: Yes, Hmmm

ca: Well sure, that's understandable...but hand on heart...I'm absolutely sure...there's no reason in the world why you shouldn't have a healthy baby.....come whatever...

835

fp: No...

840 c: And the vast majority.....I suppose in a way the problem is for you it's your first baby...it's not as if it's happened after you have three or four children...

fp: Yes...

845 c: Because in a way you have to take it on trust from me that I'm telling you the truth.....you don't have the sort of the proof sitting at home...

850 fp: That's right...

c: And I see a lot of people have this happen as a first time, and generally speaking, if you've actually had a baby, you know you can do it!

855 fp: Hmm

c: Whereas just trying to believe it must be quite difficult ..... whereas...

860 fp: Does it occur more on your first try...?

c: No...no....it's not related to whether it's your first or your eighth...

865 fp: Oh really

c: It doesn't seem to make any difference....

870 There is this age factor...

fp: Yes...

c: So I suppose if you were to analyse that.....I suppose most people have hai babies before only because they were then having babies at an older age group....do you know what I mean....?

875 fp: Yes

880 mp: Hmmm

c: But increasingly the way the world is going, women are having babies later and later....

885 fp: Yes...

mp: Yes...

890 c: Because of jobs and mortgages more and more people are having babies after 35, so increasingly we may see more and more people having their first pregnancies later.....[ difficult to hear ]

fp: Right...

335 a: The thing is these things are very common, but it's not a  
every people talk about...

fp: No....

338 a: If you were to get 100 of your schoolfriends to come in  
you would find there was an enormous number...

fp: Yes...it's amazing how many people told me they have had  
miscarriages...and when we lost the baby people came  
339 forward and said they'd had something similar...we  
couldn't believe...

a: That's right...it isn't until you say..."that's how  
happened to us..."that people feel they can say ...

340 fp: Yes, because when you're pregnant people don't like to  
give you horror stories, do they.....!

a: Well that's right...and neither do you want that to...!

341 fp: No!

But yes, I think these things going on are actually  
much more common than people believe...but it's only when  
342 it happens to you that you look into these things...

fp: You always think it'll be somebody else....

a: Has anything happened in your families at all... we  
343 usually just draw a family tree

fp: We asked, didn't we and my dad's cousin had Down's  
Syndrome child...

344 a: Right....and have you got brothers and sisters...

fp: One of each....

a: And are they fit and healthy.....?

345 fp: Yes...

a: Did your mum have any problems...

346 fp: She had one miscarriage before me...I'm the eldest...

a: And does your brother and sister have children....?

fp: No....

347 a: So it was your dad's cousin....how many brothers and  
sisters has he got...?

fp: He's got three brothers and sisters....  
 950 One's dead now....  
 c: He had two brothers and sisters or...?  
 fp: Two sisters and one brother  
 965 c: He had two sisters and a brother....and one of them's  
 died....?  
 fp: The sister's died...  
 980 c: And they had children...  
 fp: His brother couldn't have children....  
 995 c: You don't know why.....?  
 fp: No, I don't know why...they adopted there's...but my  
 aunt's got two children....  
 1010 c: Are they well...?  
 fp: Yes...  
 c: So it's further back in the family....  
 1025 fp: It was dad's cousin ...his dad's sister's grandchild.....  
 c: Right...it's along way off....  
 1040 c: It's likely to be unrelated...do you know how old the  
 mother of that baby was...?  
 fp: No....  
 1055 c: It's very very distant....and it's very common....it's  
 the commonest thing that goes wrong with chromosomes...  
 fp: Oh really.....  
 1070 c: And a lot of people in that generation...before  
 amniocentesis tests came along...because of  
 contraception, a lot of people had lots of babies and so  
 it's quite common in that generation to find a lot of  
 1085 people  
 fp: Oh right....  
 c: Nothing on your mum's side....  
 1100 fp: Well she had one sister that never had children. ...  
 c: By choice, or...  
 fp: Yes...

1005 c: Have you got brothers and sisters?  
 mp: Yes, three brothers....

1010 c: Did your mum have any problems....?  
 mp: No....

c: Have your brothers got children....

1015 fp: My eldest brother's got two twins...  
 c: A pair of twins...boys or girls....?  
 mp: And there's Tony, he has a boy....

1020 c: And your mum and dad....?  
 mp: They're fine...

1025 c: And the two of you are fine and well....  
 fp: Yes...

c: You're not cousins, not related in any way....  
 1030 You're Sarah, aren't you...  
 And your're Nigel....

When's your date of birth?

1035 mp: 12.8.63...

c: Great, fine, OK. We always ask people these things  
 1040 because just occasionally we find something that's  
 relevant...but I really don't want to go too far....

It's not uncommon to find a family with it somewhere  
 back...

1045 fp: Oh good....

c: Is there anything else you want to ask....?

fp: No, not really, it's just the future, the tests....

1050 c: What we usually do is offer to write people a letter,  
 putting these things down in black and white. ...we can  
 do that if you would like us to....and I can send you  
 some information about the tests available for the  
 1055 future....

fp: Oh yes please....

c: And if you decide to have a baby and you'd like to come  
 1060 and talk to me....just ring...you don't need to go

through your GP...

mp: Oh yes...

1055 fp: Thank you....

a: Or talk on the phone....I know it's quite a fair way to come....

1070 Some people choose to have no tests...the chances are if you have no tests, everything's fine...but then people find when they get to the point of it...they get very worried....

1075 mp: Well yes....this has taken all the excitement off now..

a: Well yes....I think it's very sad...because next time around you won't be feeling as positive about things as you would have done if this had not happened...

1080 Were they alright when you were in hospital.... ?

mp: Oh yes...couldn't have been better...

1085 fp: Yes...

a: Good

1090 fp: In fact one of the worst things was actually leaving...everyone was so nice in there....to step outside....

1095 mp: Yes...when you get in the real world you don't know how people are going to react...

fp: Most people have been very nice....but some people....young people with babies...haven't even mentioned it...I suppose I might be the same if it was the other way around....

1100 a: But that makes it very hard for you....

1105 fp: It's almost as if they want to dismiss it...it's like saying she wasn't real....but she was a real baby....and she was ours....

a: She was part of your family, and always will be....

1110 fp: I don't think some people understand that....do they...that we consider her as being our daughter....

But on the whole people have been really nice....

1115 a: And your family....you feel you have quite good support....



fp: Yes. Work have been good to me....I was on the list to  
be made redundant....which I was pleased about at the  
time...but when I lost the baby they saved my job...

1120 e: Right...

fp: So that's really good....the worst thing would have been  
to be at home in a stew about it...it was quite a while  
1125 before I went back...but to be with people all the  
time...

e: Did you have to go back to work quite soon....

1130 mp: Yes...

e: Men often lose out don't they....they don't go so much  
understanding...

1135 mp: My mate came to see us in hospital....but it was  
hard....he couldn't see that I was sick, sort of thing...  
  
They said the right things...but....

1140 fp: Men find it harder to speak to each other...

mp: They kept telling me not to hurry back....but when I did  
go back the boss started ranting and raving at me saying  
I was letting them all down...

1145 e: You went back earlier than you would have liked to...

mp: I would have liked to have stayed with Sarah as much as  
anything...

1150 I felt guilty at leaving Sarah....you get to a point  
where you think "Stuff all this, it isn't important...."  
  
...but after a while...you've got to go back....

1155 e: Have things have got gradually easier as the weeks have  
gone by....or...

fp: I think so....sometimes.....

1160 mp: ...it hits you harder...you won't forget it...it  
happened....you survive...

fp: It just seems so unfair...I couldn't believe it...I felt  
really angry....and when I was going to work....I kept  
1165 saying "I shouldn't be going to work... I should be  
leaving...." But in the end you just get it into your  
head...this it's the way it's going to be now...

1170 e: That's right...

fp: Some days I don't feel too bad...but when she's going to

be due...that's going to be hard...

1175 mp: Yes...

We're going to have time off then...

1180 a: Yes...that would be a good time to be together, because it's going to be difficult...

fp: We just learn to carry on....I'm glad at what we've done today....

1185 mp: It's been a relief...

fp: We were just beginning to wonder what we were going to do if we couldn't have children....

1190 a: It was really nothing you did, or didn't do...if you'd come to me before you got pregnant and said "How can we stop anything happening...?" there was nothing I could have told you...short of you being exposed to radiation or those sort of things...normal life...we don't understand why it happens...Maybe one day we will....

1195 fp: In some ways Down's Syndrome made it a real reason....

mp: Yes....

1200 fp: If it had only been the water on the brain...and we were chunking....I've had a bad cold...and I'd bled a little bit during that...and I'm a keen gardener...and I thought "Was it something I picked up in the garden...?"

1205 a: Yes...

fp: And all those sort of things....I was thinking "What have I done wrong...?"

1210 a: No, we think it was the extra chromosome that caused the problem...without that.. [difficult to hear]

1215 fp: So it could have been either of us, then...?

a: It could have...it was probably there either the egg or the sperm...and we don't know....and in a way...there was nothing you could have done about it...probably all of us...in our eggs and sperm....carry some sort of

1220 problem...

fp: Right....

1225 a: It's thought that every single person carries three or four potential problems...that gives rise to problems in the gene....and why some of us get away with it we don't know...it's purely chance...

1230 fp: Yes...

g: There's no explanation....

fp: Yes...

1235 g: I'll drop you a line and explain to you about the tests....

fp: Right...

1240 g: And you're very welcome to ring if there's anything in the letter...

fp: Right...

1245 Do you do the testing yourself do you?

g: I don't actually do the testing...! It's done by somebody else...The actual CVS and amniocentesis is done by some colleagues of mine who work on the 15th floor, who are obstetricians, who are trained especially in this work...

1250 fp: Are you the one who investigates the chromosomes....?

1255 g: No, I don't do that either...that's another colleague of mine! Who are beavering away in the laboratories...looking down the microscopes at the chromosomes...really clever stuff....so no...this is a real kind of teamwork thing....

1260 fp: I just wondered because you wrote the letter and whatever...

1265 g: My colleagues and I and the clinical team tend to do the actual seeing people and explaining things and organising tests, and there are other people in the team who do the clever stuff in the laboratories...

1270 fp: It's amazing isn't it....?

g: There are something like a hundred people in this department so I'm just part of a huge team...

[Discussion about whether Guy's will close and what will happen to the Department]

1275 g: Well I'm glad to have met you...and get back in touch....

fp: Thank you...

1280

## APPENDIX B

### TRANSCRIPT 2

- c: Do sit down. I'm Dr Evans. I'm sorry that I kept you, I got caught on the 'phone and couldn't get away. I'm just looking for the letter that we had I think, was it from your GP, asking if we could see you?
- 5 fp: Yes.
- c: That's right, from Dr C. Erm, and really, putting together the results of all that's happened, how are things for you?
- 10 fp: OK. I get good days and bad [fp: whispers].
- mp: *Certain things, sort of, trigger memories and it comes back.*
- fp: I had to give up work last friday and, er....
- 15 mp: *Generally not bad (no). We had lots of calls from friends and family.*
- c: Because it's still just a couple of months.
- 20 fp: Right. [inaudible]
- c: I think from any families who have, found something, it all comes as a great shock and it takes a long time.
- 25 fp: Yeah and you, you get back to everyday life, you get back to normality at certain times [inaudible].
- c: Erm, the reason for our suggesting that we could see you is to talk about what happened (um). Erm, I don't know if the results of tests that were done have
- 30 been discussed with you, but also to talk about the future (yeah) and, erm, I don't know how much you know already, but in fact nothing that I'm going to talk about, I think, is anything new or worrying for the future.
- mp: *We just spoken to, erm....*
- 35 fp: Angela.
- mp: *...Angela at Kings (right), yeah, the Harris Birthright[?] and she, sort of like, told us, erm, very sketchy obviously she doesn't know, obviously as much as you do, but, erm,*
- 40 *some of the [inaudible]*
- c: Maybe, but...
- mp: *I mean that's what apparently made the blood results come back. But I said she just*

45           *said it's bad brain tissue disorder and that's as far as it goes. It would be the best result we could have but a decision we had to make.*

          c:     *What would help me is if I could draw out the family tree (yeah) just to know where you and people are in the family. It's AP? (yes) And can I put down*  
50           *your date of birth?*

          fp:    *[inaudible] '68.*

          c:     *And, is it S? (yes, it is). Right, and can I put down your date of birth?*  
55           *It's 20th 03, '68.*

          c:     *And, the baby that you lost - was that your first pregnancy? You've not had any miscarriages?*  
60           *No, but we thought a year or two ago I may have had a miscarriage but then we decided that perhaps I hadn't. We're not too sure.*

          c:     *If I just ask for a few on S's side of the family. Are you well yourself?*  
65           *Erm, I mean apart from things like asthma, which I've had from a child it, sort of, comes and goes. Erm, I've also had, erm, a hip - Perthis[?] disease, which is, like, a hip disorder. Erm, but generally - I mean apart from that - yes. I'm not usually a very sickly person.*  
70           *OK. And do you have brothers and sisters?*

          mp:    *I have 1 brother who is older and 1 younger sister.*

75           c:     *An older brother and a younger sister? (yeah) And do they have any family of their own?*

          mp:    *Erm, G had asthma as a child but has grown out of it. Erm, and N, well N is just N!*

80           c:     *Do they have children? (no) And your parents, are they alive? (yes) And are they both well?*

          mp:    *Yes. Erm, I mean there's only things like my mother's mother had arthritis badly which mum has picked up.*  
85           *She had thrombosis.*

          mp:    *Did she have thrombosis? (yeah) And other, sort of, like illnesses my dad has had have been just, sort of, work related.*  
90           c:     *It's more thinking about conditions that could be inherited or, or passed through.*

mp: *No. I was the only one who, sort of...*

95 c: Nothing further on in the family that you are aware of?

mp: *Not that I'm aware of, no.*

100 c: Can I ask on A's side of the family, are you well? [presumably replies yes] Do you have brothers and sisters?

fp: 1 brother.

105 c: And does he have any children?

fp: Erm, yes, 1.

c: How old is the child?

110 fp: Erm, 4 isn't she?

[discusses age with mp:]

115 c: And she's well?

fp: And she's well, yeah.

c: And your parents, are they both well?

120 fp: Yeah, they're fine. Erm, well....

mp: *Your, your, erm, natural father is dead.*

125 fp: My natural father died at 42 that was through alcoholism [inaudible]

c: Is there anything you can tell us, further on in the family, that you're aware of?

fp: Erm, my paternal grandmother, my French grandmother has Parkinsons disease.

130 c: And do you know whether your 2 families are related in any way, whether you might be distant relatives?

mp: *No.*

135 fp: At least I hope not [laughing]

c: And, during the pregnancy that you lost, how were things at the start of the pregnancy?

140 fp: Very strange. Erm, the home test kits kept coming up positive (yes) and the hospital kits kept coming up negative. Erm, so in the end I paid for a blood test to have the

pregnancy confirmed for once and for all. Then I started to lose the baby at 6 weeks.

145     fp:     With bleeding. I had a scan and they said the baby was small for the dates but just put it down to the fact that maybe I'd ovulated at the time, erm, and I stopped bleeding and everything. But I had lots of little complaints like, I had indigestion which you don't usually get in the middle of pregnancy. Erm, headaches, I had lots and lots of headaches. I just generally didn't feel....

150     mp:     Yeah but at the time, erm....

155     fp:     ....I just put it down to, you know, this is the first pregnancy, you never know what to expect.

160     mp:     ...At the time I sort of 'worked' for BT and I was considering taking redundancy. I was looking for another job, erm, so we'd just moved and we had all the stress of money and everything as well, so, I mean, I don't know if that would play any part of headaches and stress and everything.

165     fp:     I just generally ....

170     cp:     I would come on to say probably not, not directly. Erm, when was it that they first thought there might be something wrong?

175     fp:     Well I went for my 12 week scan and everything, they said everything was fine. The baby again was [inaudible] which just rearranged my, erm, expected delivery date (umm humm) They put it down to ovulating.

180     cp:     Was this at Farnborough?

185     fp:     Erm, no that was actually at Bromley, Masons Hill, the ante natal clinic. That was just to check the dates (right). Erm..

190     cp:     You were under Mr H?

195     fp:     Yeah. And the first we knew that there was something wrong was at the 20 week scan, and...

200     mp:     That was at Farnborough wasn't it.

205     fp:     That was at Farnborough, and they said that there was something wrong with the foot.

210     cp:     And was that where you went to Kings?

215     fp:     That was Kings [inaudible]

220     cp:     And everything happened from there.

190 fp: And everything happened from there.

mp: [inaudible]

fp: He told us it couldn't get worse. It did.

195 mp: *Wasn't it about 2 weeks between the first scan ....*

fp: No, we had the first scan and they said, we saw what's it [?] and he said it was strange because there wasn't any one thing that he could say 'well yes, this is definitely this or yes, this is definitely that' he said it was all too.. because the trunk was twisted, the chest was concave, the ventricles in the brain were too prominent, but not (umm) seriously so. He just couldn't seem to put his finger on it.

200 mp: *The heel on 1 foot was starting to extend didn't it.*

205 fp: It didn't, not on the first scan.

mp: *Not on the first scan no.*

fp: Erm, and then they took blood from the umbilical cord to see if there was a chromosome....

210 a: And that showed up?

fp: And that showed the abnormality. And when we went back the following week to have blood tests ourselves, they said had you thought about it. And we'd obviously thought about it. If the baby was brain damaged then, we would terminate, but if it's just bits of [inaudible] we'll carry on with the pregnancy. And they scanned again and found that things had got a lot worse. The second foot was actually deformed, erm, the head was....

215 mp: *Something round the side of the head.*

fp: Something at the back of the brain was only half of what it should have been.

220 mp: *Strawberry shaped head.*

fp: So basically the baby hadn't grown from [inaudible]

225 mp: *No. I mean even at 20 odd weeks it still only weighed 3/4lb, so it was still very small.*

230 a: I got the results of some of the tests on the baby. I don't know if you went back to the Harris Birthright Centre at Kingston and they talked to you about them.

fp: We went back to Farnborough and they'd lost the results there. We've never been told the results.

235



240 c: I've got the results here and I can certainly talk through them with you. There's nothing, erm, new or very worrying from your report. And I'd certainly be very happy to give a copy of this to you if you wanted it. Some families do and some families don't.

fp: I'd like to see it.

245 c: Did you see the baby after?

fp: Yes [whispering]

mp: *Yes we've got a photograph and we've got like a cot card and other bits and pieces. We weren't going to initially were we? You alright? We weren't initially, but we thought it helped to, sort of, like grieve and everything.*

250 c: OK. It just brings it all back.

[fp: obviously crying]

255 mp: *As I say, this has been worrying A for quite a while, because leading up to it, because she didn't know - it's all been nagging there, sort of brought it all to the fore again.*

260 c: Coming today?

mp: Yeah

fp: I'm sorry.

265 c: That's alright. I'm just going to reach into the corner for something. I know that coming up just brings it all back to the fore.

mp: Um, yes.

270 fp: Thanks [presumably c: hands her a tissue]

mp: *'Cos the last couple of days it's been, I mean it's always been nagging, all these sort of things trigger it.*

275 fp: I think, you know, it's because I was supposed to give up work as well and this, sort of, goes to [inaudible].

c: It takes time. Sometimes it will ... a long time, and it never goes away.

280 fp: I hope it never goes away.

c: And no-one would ever expect it to do that. Just with time, it perhaps becomes a bit easier ...

285 fp: Yeah, you accept it. You don't forget it but you accept it. At least I had the baby - that helped.

290 c: We don't know why it happened but the results of the blood test that was taken from the babies chord showed an abnormality in the baby's chromosomes. I don't know if you've seen these kind of pictures before?

fp: No.

295 c: They're details of [inaudible]. But usually there are a set of 46 chromosomes (right) in a set of chromosomes (right). And they're in every cell of the body - they carry all the genetic information that a person has (right). And our tests are still very basic, all we can do is look at them and count them up and make sure that most of the pattern is normal. If there's an x and y, it's going to be a boy, and a girl would be xx for example (yeah). In the tests on your baby, I'm just looking at the report that there were, erm, they found that there was a problem with one of the number 17's (right). I don't know if that number was mentioned?

300 mp: Yes, 17 and 17 p's[?]

305 c: Right. And what that means is that one of the chromosome 17's, which are these pair here, looked normal; but the other one in the pair, and there are 2 because one's come from mum and ones come from dad, (yeah) was abnormal in its appearance, particularly on the top part - up here (right). And what it seems to be was that there was both additional material - additional chromosome material - the cause of which, the source of which, we still don't know (um hum). And that also part of number 17 may have become broken off (right). So, if you just sketch out in a diagram, the chromosome normally looks like this, it's a, kind of, large detail. It has this stripey pattern because you can treat it with chemical stains - can you see the stripe (yes)? It just looked that part of it had been lost and there was extra material in there.

310 mp: So it had lost some and gained some other.

320 c: That's right. And one cause of that, that we often think, is that maybe there's been a switch round in the chromosomes from somewhere else, that part of number 17 has been switched over to number 6, for example, and back again. And that was the reason for testing your chromosomes to see if there is any tendency for that to happen (right) and both of your chromosomes were entirely normal. So we're really very happy that whatever did happen to the baby was not one that was passed on by you, or it's not, kind of, inherited or genetic in that sense. It was to do with the genes and chromosomes but it wasn't passed on from either of you.

325 fp: I see. What's the likelihood of it happening again?

330 c: It's very small, I'll come back to that (OK). What we don't know is exactly what the abnormality with the chromosome 17 is in detail.

mp: *Um hum. I mean, I know it's quite a long time post, but I mean, would you be able to find out from - on the studies on that chromosome - or is it...*

335

a: Not yet. I mean, our knowledge of chromosomes is still relatively crude in that there are something like 70,000 genes spread across all of the chromosomes. Each gene is a different genetic instruction (*um*). What we don't know is all the genes on number 17, for example. We know that, and this is nothing to do with your family, but number 21 is involved in Down's syndrome, for example (*um*). What we don't know is what number 17 does. But also, not only what happens if a part of 17 is lost, but we don't know where the other chromosome came from, number 17.

343

345 mp: *Uh huh. You can't trace to where it, yeah, to the origin.*

a: We can't do those kinds of tests yet. (*right*) And the information that you were given at the time is that we know that in babies that have problems with chromosome 17, in the area that your baby had (*um hum*), can have quite severe brain damage (*right*) and the medical condition is called Lysencephaly[?]. We don't know for sure that your baby had that (*no*) condition, but really, chromosome problems like the one that your baby had, do carry a high risk of abnormalities (*um*). When one does a scan, one can only look at the most obvious outside features.

350

355 mp: *Um, physical, yeah.*

a: That's right, of a baby. One cannot say how the baby will be when they're born, or how they will develop. But usually these things are associated with learning difficulties and some degree of mental handicap of a variable degree. And I think that's what would have happened if the pregnancy had continued.

360

mp: *That's what, I mean, Professor N, he said that that was, that's what came back after the results, it was 17. But he said because there were so many abnormalities that didn't all connect with each other (um) it may just, it might have been 3 or 4 different physical and mental things (right), so I mean ....*

365

a: So, the other word for Lysencephaly[?] is a condition, nothing to do with your baby, called the Miller-Decker[?] syndrome. And we don't, we can't say that your baby had that (*um hum*) particular condition. But certainly those babies have severe learning problems. They don't have the physical abnormalities but they have a chromosome problem in the region that your baby had.

370

375 bp: *But she had quite a few physical [inaudible].*

a: And I think the combination of the malposition of the feet and partly of the way the hands were held, and the dilatational opening of the ventricles (*um*) these gaps within the brain, suggested that the chromosome problem was having an effect and it would have been very marked (*right*).

380

mp: *Erm, would that also have something to do with, I mean, when the baby was actually born, the actual placenta broke up as well. Could that be connected towards....*

385 c: I'm guessing from what we know from the reports (*um*) and what you've told me. But I think that some of the warning signs were there earlier on, that this was a pregnancy that was not going well.

mp: *Yeah, not going well at all.*

390 c: And that's why the baby wasn't growing at the right rate. Er, some families have small babies; that's just that. But I think the number of problems that were added together and the fact that the placenta was not functioning well are all signs that this chromosome problem was a real one (right), not a, kind of, coincidence, and it would have meant very marked problems for the baby (*um*).

395 fp: They did say last time they didn't think she would survive full term with the placenta and because she'd stopped growing

c: Right. I don't....

400 mp: *She put on literally, well, nothing....*

fp: She had a [inaudible]

405 c: I don't have all the, kinds of, figures here for how the baby was. Er, in that she weighed about 300 grams and I can't say off hand what size a baby should be at that, at that stage.

mp: *I think it's [inaudible]*

410 c: It's half.

mp: *Um.*

415 fp: They showed, Andrea showed us on the graph, sort of 2 points in a week and she showed us where it should have been and where it was.

c: So the baby was.....

420 mp: *Yeah, I mean, 2 crosses which were on top of each other, whereas they should have been a couple of inches apart on the graph; they showed us.*

c: I can go through this report with you, if you like to.

425 mp: *Yeah.*

fp: Yes please.

mp: *So would it be possible to have a copy as well?*

430  
 a: Yep.

mp: *I mean, not we want it to ever happen again, but just in case, and then we can actually, sort of, come forward and say look, we had this....*

435  
 fp: [inaudible] (yes).

a: Erm, I'll copy both pages. The, the first is just a kind of background information (um) and this was tests done on the baby at Kings College Hospital (um hum) (oh right), after you ended the pregnancy.

440  
 mp: *Was it when the baby was sent back to Kings? Oh right.*

a: And it, it just talked about the results of the chromosome number 17. What the findings, erm, for the baby were, was that, erm, the baby weighed 300 grams, and so - you felt that was half the size the baby should have been.

445  
 fp: I was 21 weeks.

a: Right. Erm, that, er, the doctor who, who, who did the report felt that that was smaller than one would expect (um) at that stage. Erm, she actually says it's less than 20 weeks size rather than 21 or 22 weeks which you should have been at that point. Both of the feet were abnormal and there were various medical words (um hum) and there's the medical word which is talipes[?] (um).

450  
 mp: *Yeah, we've heard that one.*

455  
 a: And really what that means is that the feet, rather than being pointed out as it should be, are very much pointed inwards (um hum) and turned in.

mp: *Yeah. That's what showed on the scan wasn't it.*

460  
 a: The fingers in the hand were held in an abnormal position, with the fingers flexed - that's creased over (um) and the first finger overlapping the second. So, really, this kind of. [demonstrating].

465  
 mp: *Yeah, it was all twisted as well.*

a: That's right. (yeah) And often that can result from abnormal brains or nervous systems in the, in the baby, that the hands and feet are not held properly. That the baby's face looked normal, but sometimes one can recognise in a baby's face a particular syndrome that the baby looks unusual or different. Erm, and really the report then goes on to, erm, list out the other parts of, of the baby which were normally formed (um hum). And .....

470  
 fp: Something on the Kings report that, erm, something to do with the bowel.

475  
 a: Erm, the bowel here appears normally formed and also when the bowel develops

it rotates (*um hum*), that the stomach comes to lie here (yes) and the bowel lies below it, and that all seemed to be happening normally.

480 fp: What about the chest because they said that that was concave.

485 c: I'll come on to talk about the nervous system and the brain, but there are several things that one sees on a scan because the baby is still formed, as it were, and, but during the process of delivering the pregnancy there can be quite a lot of changes (*um hum*) that are included, which may not be reflecting of how the baby was (*um hum*). And really all that they found of the, the chest was that the lungs were forming normally and they've made no comment about the chest wall.

490 mp: *Um. 'Cos I mean from the scan, with a - like a cross section, and it was, sort of, like, like an 'M', you know, it was very, very concaved (umm) round the centre of the chest. I mean that's what one of the ... pointed out, wasn't it.*

495 c: Brum, as I say, that's not mentioned specifically in the report, but it may be that, er, Dr Newbold who's done the report, is used to seeing abnormalities either as a result of the pregnancy (*u n*) being delivered and, in fact, going on to talk about the brain, erm, that as a result of, erm, the pregnancy ending, the brain tissue starts to soften anyway - on its own (*um hum*). So, she can't say whether the tests show what happened before the baby was delivered or as a result of the delivery process itself. (right). So there is no detail about the individual structure of the brain, but we know from ultrasound scans, like the ones that you had, and even brain scans that you do on adults, that it gives you no idea of what's going on (no) within (no) the actual function of the brain. But what she does comment again, is that the, the ventricles - these are the kind of caves within the brain that make the brain fluid, were larger than they should have been, which confirmed Mr N's findings.

500 fp: She said there was another part of the brain which she obviously couldn't see, but, it was at the back and it began with a 'v'.

505 c: The vermis.

510 mp: *One of the lobes or something.*

515 fp: It was half of the size that it should have been.

c: [sighing] You've got, I think, kind of, two opinions (yeah). You've got Mr N's, erm, getting a kind of second hand view through your tummy, through the scan. And you've got Dr N, who, erm, could only report on what she saw.

520 mp: *Yeah, physical.*

c: .....And she said that it was there, but it's position may have changed (yes) through the delivery process.

535 mp: *They said it was there, they said it was just under-developed, sort of, for how old the baby was.*

536 c: I don't think I've any doubts, from what I've read, that there were serious problems already there. And that, that - I don't know whether one can say the pregnancy would have miscarried itself. Sometimes chromosome problems can affect the heart or other vital organs that mean a baby would not survive through the pregnancy or at delivery. I think that whilst there's nothing listed here that would have, erm, meant that the baby could not survive, I think that there was a very high chance that the baby would have had brain damage from this abnormality.

537 mp: *Is that the information we were given by...?*

538 fp: *We made the right decision.*

539 mp: *Yeah. I mean you wouldn't say 100%, it is about 80, 80% chance?*

540 c: It's difficult to put figures on things (um). I can certainly give a copy of this to you. I mean there are some medical words in there, but I think I've been through the, kind of (yeah) (um, yeah, medical part. I mean I can also give you this which we actually got through from the laboratory that did it, and, and which is the result of the chromosome test (um), for you and for your daughter. Going back to what I said is that we looked to see if we could see this chromosome problem in either of you, and it wasn't there. So what we assume is that, at some point in maybe the egg or the sperm, when the chromosomes were forming from your egg cells (yes), that this change happened and we don't know why it happened. And, I think people look back and rack their brains as to what they did, or didn't do.

541 mp: *Yeah, well we've been all through that haven't we.*

542 c: And if we knew, we would tell you (um). But there's no pattern that we know of.

543 fp: *Could it be an external thing? From, sort of, something internal, you just can't....*

544 c: There is no set pattern with any family that we know of. We have families who are involved in, erm, medical radiation - who are involved in X-Rays, who wonder about X-Rays; who wonder about handling chemicals or drugs or, erm, computer screens and all the .... There's no pattern (um), because for every family that we see here, there are a hundred families who have done exactly the same thing, and nothing has happened.

545 mp: *Because as I, as I said earlier with my hip disease. I mean up to the age of 12 or 13, I would have at least 1 or 2 X-Rays a month, sort of like, to see the development of my hips - for about 3 or 4 years.*

546 c: The good thing, you know, about boys is that sperm that they make has newly

575 been made and replaced (*yeah*), so one would really, kind of, think that whatever X-Rays were given years ago, the effect may have affected so at the time, but wouldn't have affected the sperm now.

580 fp: The only thing I can think is that [inaudible]. And the fact that in early pregnancy I smoked [inaudible].

585 c: Not that we know of. We've got our own, kind of, concerns about smoking generally, but I think that, erm, for what you've, you've gone through, it's not surprising if you're back smoking at the moment.

fp: I am

[both fp: and mp: manage to laugh]

mp: *I didn't mean to do that!*

590 fp: No, I'm going to give up again.

c: I can't load it against you and say that you must not smoke. It's associated with some families with smaller babies, but that wasn't the cause here, it was something else.

595 mp: *I mean going back to .....*

fp: [inaudible]

600 c: So the likelihood is it is very, very unlikely to happen again.

fp: Had I miscarried when I'd already started to miscarry, I'd have been none the wiser (that's right). Picked myself up and (that's right) then 3 months later started again.

605 c: Without ever knowing ...

fp: Without ever knowing about it.

c: And probably quite a number of miscarriages happen to lots of people, of something like this, that are either more severe, if you like, in the effect on the baby.

610 fp: Although, in saying that, they were talking about it the other day and my cousin had a baby, erm, she had 1 baby, then her second baby she went, they were doing the scans at 4 months then, not 12 weeks, and she went and the baby had died. And someone said to her she should have miscarried, it was a 1 in a million, she should have miscarried. He said they needed to do a D&C, but that baby wasn't going anywhere. Some people just don't miscarry. Never know. She should have miscarried, I should have miscarried.

615

620



625      c:      97%, 98% of mothers go through a pregnancy without any problem at all, and  
 it's just the one or two who have something which often is very minor, but  
 sometimes it's more major. And I don't know why it should be.

630      fp:      [inaudible]

635      c:      But from the tests that we've done it seems very unlikely that it should happen  
 again. (um) And as you've said, there's...if we'd not done these tests we'd never  
 have known (um). There's nothing else that we really needed to do, or need to  
 do for the future, except to say that we can't say that it definitely won't happen  
 again, but, as much for your peace of mind, is that we would offer to do these  
 tests again if you wanted.

640      fp:      I was told about the CPS test is that....

645      c:      Is that through Kings?

650      fp:      Yeah.

655      c:      Ermm, so, next time, when you're ready yourselves, there's no particular advice  
 that we would give to you, that...you know, we're 99% happy that this thing  
 won't happen again. But that if you're concerned, and for your peace of mind,  
 through Kings we would offer to do tests if we can, but the only thing that one  
 has to consider is which tests are more useful and more important and which tests  
 are safer.

660      mp:      *Is there any, sort of, particular tests that would be used to identify specific things.  
 That are going to be more, erm, not dangerous, but more, sort of like, erm, I suppose  
 dangerous - likely to cause a miscarriage.*

665      c:      Um. As I say, nothing from our tests has shown any real increase in risk or  
 chance next time. There are a, a battery of tests that all mums go through when  
 they book blood tests and so forth, but the only thing that one would suggest  
 checking is that the baby's chromosomes, if you wanted to have the baby's  
 chromosome checked, erm, earlier on in a pregnancy than happened last time.

670      fp:      Yes.

675      mp:      *Oh yeah, definitely.*

680      fp:      I couldn't go to 20 weeks again and find out - I couldn't do it. I couldn't go through  
 it again, I really couldn't.

685      c:      That the choices run between having a scan, but the scan is not very precise early  
 on. Some mothers have smaller babies and 9 out of 10 times it's just a small  
 baby, it's not this (um). The advantages of scans, though, is that they're very  
 easy, they're very safe. The choice of tests to have, erm, to check the baby's  
 chromosomes directly is to take a sample from the pregnancy. The test that you

670 had can only be done quite late on in the pregnancy when the baby is big enough  
to take a sample from the baby's cord. The other 2 tests that there are; one of  
the tests is called amniocentesis, and the other test is called the CVS test, which  
is what was mentioned to you at Kings. I can tell you a little bit about both tests,  
which have advantages and disadvantages. The amniocentesis test is one that  
675 more mothers have heard about and that's the test that's usually offered to older  
mothers to check for Down's syndrome, to check the chromosomes, particularly  
number 21. That test is usually done around 14, 16 weeks into the pregnancy and  
involves taking a sample of fluid from around the baby. One has to wait for the  
cells that float in that fluid to grow in a laboratory and that can take 2 or 3  
weeks to give a result.

680  
mp: *So you're still looking at, son of, 19 or 20 weeks.*

fp: That's too far on.

685 c: So you're round 17 to 19 weeks, yes.

fp: [inaudible]

690 c: So the amniocentesis has a disadvantage that it's a late result (um) it's a long time  
to wait for that result. And if there were to be problems, you're late on as you  
were.

mp: *So you have to go through the whole thing again, going through labour.*

695 c: It means going through a labour to have the pregnancy. The CVS test and I can  
give you a leaflet on these tests, has the advantage that it's done earlier in the  
pregnancy. It can be done round about 10 or 11 weeks and it should give a result  
in about 2 weeks from the time that the test is done, so you should have a result  
by the time you're 13 weeks, which is still early enough if there is a problem, to  
700 end the pregnancy with you asleep.

fp: Right. But there's more risk with that is there?

705 c: That's right. So it has the advantage that it's an earlier test. The disadvantage,  
really, of both the tests is that they both have a risk of miscarriage. For the  
amniocentesis test it's probably less than a 1% chance, by that I mean that of 100  
mothers who have the test done, 99 have no problem from it. But we are  
concerned, however carefully the test is done, 1 mother might lose the pregnancy  
through that test. And one has to, kind of, think about what the chances of  
710 finding a problem are versus the risks of miscarriage. And what we would never  
want is for you to lose what would have been a normal pregnancy, through  
having a test done. The CVS test is done earlier, probably, erm, part of the risk  
there is that, because you're earlier, some pregnancies would miscarry anyway,  
at that early stage. Erm, but the risk of miscarriage is about 2% or 3%, so it is  
715 slightly higher than the amniocentesis risk.

fp: What about blood tests that they announced in the news last year.

120 c: Um. There is a lot of interest in blood tests and in scans. Erm, Kings have got a project going that scans the baby, looking particularly at the sides of the baby's neck and the thickness of skin and fluid round the neck, as a, kind of, marker or indicator of whether there might be a problem. The difficulty about those tests, I guess, for you, is that those tests are really directed towards Down's syndrome as a (oh) particular condition (*um*), and problems with number 21. And we could make no promise that doing the tests would .....

125 fp: [inaudible]

c: ...would cover this kind of problem.

130 mp: *So it definitely wouldn't have Downs, but it wouldn't cover anything else.*

c: That's right.

135 fp: I had a [inaudible] test and they told me it definitely didn't have that, but didn't take account of what she did have.

c: And, it doesn't give you a 'yes' or 'no' answer. It just says to you whether it's more or less likely.

140 fp: Um. That's the blood test they were talking about last year (yes). Yeah.

c: Yep. And that, erm, it might change your risk from 1 in 600, at your kind of age, to 1 in 1,000. But really, if you wanted to know definitely, you'd have to have some test done directly on the pregnancy.

145 fp: [inaudible]

150 c: But you have to weigh...put in your mind as well, that if you have no test, if you have no test, there's a 99% chance that this will happen anyway. (*um*) I mean that's difficult to.....

155 mp: *But I would never be happy whether the tests come out negative or otherwise, until actually holding our baby in my arms, so....to know that it's 100%. I can't accept, I mean I know medical science and everything, but still till it's actually laying there. You see the tests, I mean, I can only, well - it's down to A. really, to make....*

fp: It's a horrible decision to have to make.

160 c: You don't have to decide anything (*no*).

fp: No, I know, but - I don't know, you just think - it was a 1 in a million chance and it happened to be this time, whatever. I know that's not [inaudible] it's a 1 in a million chance that I had developed an infection after the baby was born and I had to go back

765 for a second D&C and, er, that was a 1 in a million as well, so my luck at the moment [laughing] is pretty, erm....

770 c: The 1 in a million, I mean, 1, er, these chromosomes are commoner than that (yeah) and if you've been through something like, erm, the delivery, you are more prone to infection. But, erm...

fp: It just seemed [inaudible], first the baby (umm) then having to go back, then they couldn't find the report and - just one thing after another, it was just...

775 np: *I mean since the baby, this is the first time we've actually had anyone sit down with the report, and tell us exactly what's going on. It's been lost so many times and then been relayed by receptionists or whatever.*

780 c: Let me go and copy that for you (um hum). I'm just going to reach behind you (right) to give you something. This is a leaflet that's been produced here, which talks about the CVS test. I'll go and find one about amniocentesis - we've run out here at the moment (right), and I'll come back to you with these in a moment.

np: *That's great, thank you very much.*

785 [c: leaves room. He is gone for approximately 2 1/2 minutes and there appears to be no conversation at all between fp: and np:]

790 c: This is a leaflet on the amniocentesis test (thank you). Erm, it really just goes over part of what I've talked about and some other things.

fp: So what happens now? We've, erm, we've started trying for a baby again, so when I get pregnant do I contact Kings, do I....

795 c: I'll do Kings, leave it with you.

fp: Angela said, 'phone me when you're pregnant and we'll sort it out.

800 np: *And we'll take it from there.*

c: Right. OK. Erm, mostly it depends on what you'd like to do. Erm, I think as soon as you, you think you're pregnant and you can confirm it with one of these predictor tests - they're usually very reliable.

805 fp: Yeah, they were this time. I mean they kept coming up 'yes', the hospital kept coming up 'no', I didn't know what was going on.

810 c: Right. Erm, Kings set-up may vary, but, we have a rather parallel system here; in that we like mothers to get a, a, a scan to confirm the pregnancy, also to date them before they come to actually have any test done (yes). So, I don't know whether Kings would see you straight away, or if they'd ask Bromley to arrange a dating scan for you. And either you or your GP can do that (right). And then

81.5 it's really for you to decide which test you want. Ermm, and from what you were saying, I think you're favouring the CVS test, which Kings can do for you (right). And they will either send the sample to us, or to another laboratory. They, they vary as to which laboratory they use (Right. Oh, OK). But you don't need to have a directly specific contact with us or myself. We're here as a, kind of, advice and information - and what I can do is I'll write to you, putting into a letter what we've talked about (right), but leave it up to you (*um hum*). But if you'd like to come back, either when you are pregnant or to talk about tests, then we'd be very happy to see you (right). But I think as Kings have offered to see you, then you should really contact them.

82.0 fp: So we just contact them direct (yeah), don't need to go via the GP or...

82.5 ca: Not if they're happy about that. (right) Strictly speaking it's nice to let your GP know.

83.0 fp: Well the thing is, we're right, we've just moved, so I've got to change GPs which is a real pain because our GP was wonderful about all of this and it's nice to know that...

ca: Is that Dr Collins?

83.5 mp: Yeah.

84.0 fp: Dr Collins, yeah.

ca: I know it's a good practice.

84.5 fp: It's - he's lovely and it would have been nice to know that if I got pregnant I could just go in and say "I'm pregnant" and not have to explain....

ca: You don't know the name of your new GP or did you give it to...

85.0 fp: Well, I haven't registered yet. It's Dr C Y, is it, in Beckenham.

ca: I mean if you'd like to, kind of, call us sometime, I can easily send your papers on to (right) that doctor.

85.5 fp: Right, OK. Well I think I'll, sort of, register, erm, I need to register with her first. I've got to go down there apparently, and do it in person.

ca: What I'll do is, I'll write to you and I'll - in my letter it'll talk all about what we've discussed and really that's the same as a doctor's letter (*um hum*) and you could say I've been to Guys, and that's what they said - I could be offered these tests.

86.0 fp: Right, and do it that way. That's probably best.

ca: This is the, the report that I talked about. Again, er, you're very welcome to have

it but if there's anything that, that is in there that you don't understand, please get back in touch (Thank you, yeah). Erm, I think sometimes reading it through it does seem very stark (*um*) Erm, about the baby being [inaudible].

866      *fp:*      Thank you. So basically, just to summarise, there was nothing wrong with us to indicate that...we could have caused....(that's right). What went wrong was just something - one of those things. [inaudible]

870      *mp:*      *That's basically really what, erm - sort of, put our minds at rest.*

*fp:*      [inaudible] A lot to think about (*umm*). Thank you very much.

875      *ca:*      You're welcome. As I say, I'll be in touch. (*right*) And, erm, either I can write to your new GP once you've registered, or just take these. That is a long...

*fp:*      OK, that's lovely. Great.

*mp:*      *Thanks very much for your time.*

880      *ca:*      That's alright.

*mp:*      *So are we going to see Mr [?] after the consultation, the, erm....*

885      *ca:*      Yes. Erm, I'll do things outside now or he'll, I think, arrange to see you at home.

*fp:*      Oh right, so....OK.

*mp:*      *Oh right.*

890      *ca:*      If he's not outside I'd just go.

*fp:*      Right, OK. [laughing] Escape while we still can! Thanks very much.

895      *mp:*      *Thank you very much.*