

## **Handout #8**

### **Practice Interpreting Dialogues**

### **English-English**

#### **Instructions**

These exercises are designed to be used in a small group of four people. Choose one person to play the role of the Genetic Counselor (GC), one to play the role of the patient, one to interpret and one to observe.

The interpreter may NOT look at the script.

Start with Dialogue #1. Genetic Counselor, start by reading your part. At the end of each paragraph pause to let the interpreter interpret. Do not stop every after every sentence, just at the end of the paragraph. Then the patient reads, and the interpreter interprets. If the interpreter uses a hand signal to ask you to pause, do so. If the interpreter intervenes, respond as you think the Genetic Counselor or the patient would. Observer, mark on your feedback form any places where the interpreter adds, omits or changes meaning.

Interpreter, remember that you are interpreting for meaning, not words. If the speakers go on too long, use your interpreting techniques to get them to pause. Ask the meaning of words you don't know, just as you would if you were interpreting. **DO NOT STOP THE DIALOGUE TO DISCUSS VOCABULARY**; there will be time at the end.

When the first dialogue is finished, have the interpreter critique his or her own rendition. Then have the observer provide specific feedback to the interpreter. Where was meaning added, where was it omitted, where was it changed? Where did the rendition sound awkward in the target language? Was there specific vocabulary that caused the interpreter to stumble?

When you are done giving feedback switch roles and go on to Dialogue 2. Continue this pattern till everyone has had a chance to interpret.

#### **Interpreter #1**

Counselor Hello there! How are you doing today?

Patient Fine, fine, a little nervous. I've never done this before.

Counselor Sure, sure, is there any anything specific that you're nervous about, or just not sure what we're going to talk about?

Patient I just don't know what this is all about. But my doctor sent me, so here I am.

- Counselor That's often the case. I know your OB referred you, and sometime they don't explain too much about what today's appointment is for.
- Patient She just said I should come and talk to you because I'm old to be having a baby.
- Counselor Yes well, what happens in genetics is that everyone who's over 35 in their pregnancy gets sent to us, just so we can talk about some things that they are at higher risk for because of their age. It's not that you're "old" or that magically there's such a huge risk, but there are a couple of things that there could be higher chances of, so we just like to talk about those things and what are all the different kinds of tests that we could do to find out more.
- Patient *(a bit confused)* OK
- Counselor So, basically what we'll do is I'll start off by asking some questions about how the pregnancy has been going, then we'll go through your reproductive history and your family history as well to make sure there are no risk factors in this pregnancy that we would need to worry about, and then we'll get into discussing the usual screening tests and ultrasounds and other things like that that we'd consider doing in a pregnancy. Does that sound like a good plan for today?
- Patient OK
- Counselor And other than that, what do you think your main questions or worries are that you want to talk about today?
- Patient Well, I don't really know anything about this genetic stuff, so I don't really know what to ask.
- Counselor Sure, well, we'll go with the flow. Feel free to ask any questions as we go along. Most people aren't very familiar with genetics until they have an appointment like this, so we'll start at the beginning with the basics of genetics and I'll explain everything as best as I can.
- OK, so this is what number pregnancy for you?
- Patient Uh, well, this is my fourth child.
- Counselor And have you had any miscarriages or terminations?
- Patient I had two miscarriages. What's a "termination?"
- Counselor If you chose to stop the pregnancy or have an abortion.

- Patient No! No, but I did have two miscarriages.
- Counselor OK, and how far along in the pregnancy were you for those?
- Patient The first one, oh, I don't know, I was, I think I was, oh maybe I was four months along, and the other one was earlier, maybe three months.
- Counselor OK, and for either of those, did they ever have any idea of why that happened? Was there an ultrasound that was concerning or was it just random and they didn't know why?
- Patient Well, this was back in Mexico. We lived out in the country, and we didn't have all these tests back there.
- Counselor I see. OK. So you have three children that are living. How old are they?
- Patient Yes, I have two boys and one girl. The boys are 18 and 16, and my daughter is 9.
- Counselor Perfect! And they're all in good health? None of them were born with any issues or have any major medical problems?
- Patient My daughter seems to get a lot of colds. One right after another. She always seems to have something.
- Counselor How often does she get these?
- Patient In the winter time, it could be two or three times.
- Counselor I see. OK, well, regarding this pregnancy, I see you are at about 12 weeks from what it says in the record that the doctor has sent over to us. Is that right?
- Patient I guess so.
- Counselor And so far, has the pregnancy been going OK? Have you had any bleeding or spotting?
- Patient No, I haven't had any bleeding, but I've been throwing up all the time! All the time! Every hour I throw up! It's a real problem where I work. And my feet are getting swollen.
- Counselor Wow, that's not good, is it? Make sure you talk to your OB about that, because they can often give you something to help with the feeling nauseous all the time. For a lot of women, that improves once they're out of the first trimester of the pregnancy, so we'll cross our fingers that that

will happen for you.

Are there any medications that you are taking now related to the pregnancy? Any vitamins?

Patient The doctor gave me some vitamins to take. Nothing else.

Counselor OK, and any toxic exposure to anything during the pregnancy like alcohol or drugs?

Patient No! I don't drink and I don't take drugs.

Counselor Great! Then, other than feeling sick, you've been doing OK.

Like I mentioned, another thing we like to do in genetics is take a look at the family history and so what I'm going to do is to actually draw your family history on this paper. We do that so that we can see whether there's anything hereditary that we'd be concerned about either for your health or for baby's health and to see if there's anything we need to do any testing for.

So, all your pregnancies, are they all with the same partner or with different partners?

Patient All with my husband!

Counselor OK, and how old is he?

Patient He's three years older than I am, so he's 40.

Counselor And he's in good health? Anything he sees doctors for?

Patient He has a lot of pain in his lower back, so sometimes he takes pills for that.

Counselor OK, and does he have any children from any relationships before he married you?

Patient Not that I know of!

Counselor And how about you? Are you generally healthy? Is there anything that you see doctors for?

Patient No, before I came to this country, I didn't really see doctors for anything.

Counselor Well, let's start with your side of the family. How many siblings do you have?

Patient I have three brothers and four sisters.

Counselor OK. And the same mom and dad for everybody?

Patient Yes.

Counselor And all your brothers and sisters are healthy?

Patient As far as I know. Most are back in Mexico, and I don't get to talk to them much, but the last time I talked to my sister, she said everyone was OK.

Counselor Fair enough. And do all of them have children?

Patient Well, let's see. My oldest brother has four kids, then my sister has three, my next oldest sister has two, the next oldest has seven, then two, then four, and the youngest just got married.

Counselor OK, so lots of nieces and nephews then! And are all of them healthy? Nobody was born with any problems? Anything major you've heard your brothers or sisters mention?

Patient No, they're all pretty healthy, as far as I know.

Counselor And have any of them had any problems learning?

Patient Well, I have one niece – my oldest sister's youngest – she's a little slow. She's such a sweet kid, though.

Counselor How old is she? And when you say she's slow, can she walk and talk, or . . .

Patient Oh she can walk and talk! She just didn't do well at all in school. My sister sent her to school for a few years, but it just didn't work out, so now she stays home and helps my sister around the house.

Counselor Did they try to put her in a special classroom?

Patient No, they don't have those in our town.

Counselor I see. And does she have any other medical problems. Or just with learning?

Patient I don't know.

Counselor When she was born, did she need any surgery, maybe for a heart problem?

- Patient I don't think so. But she was born at home in our town, so maybe they wouldn't have known.
- Counselor Yeah, that makes sense. And does she look the same as her brothers and sisters, as the rest of the family?
- Patient (*shocked*) You think maybe she has a different father?
- Counselor Oh no, not a different father! But sometimes in genetics we ask these questions because if a child is a slow learner because of genetic factors, sometimes that can cause their faces to look a little different or sometimes they have other medical problems. That's why I was asking those questions about her.
- Patient Well, now that you mention it, her face is more round than everybody else's, and her eyes are more slanty.
- Counselor OK. Well, when we think of those kinds of things in the family, sometimes there can be a genetic reason. You know, someone can have a specific genetic condition that is causing them to have an intellectual disability or to look a little different from other people in the family. Sometimes, these are just things that happen randomly and don't necessarily run in the family. It's a little hard to say without knowing more about her whether she has something that we would be concerned about for you. Probably nothing that we would be too worried about, since your niece is just a cousin to this pregnancy, but if it's something that worries you, you could ask your sister more questions, ask if the child has ever been diagnosed with something specific, then I could tell you more accurately. But it's hard to say without more information about her.
- Is she the only one in the family with learning problems, or who couldn't learn to walk or talk properly?
- Patient No, everybody can walk and talk.

## **Interpreter #2**

- Counselor OK, and how about your mom and dad? Are they still living?
- Patient Yes.
- Counselor And are they in OK health for their age?
- Patient My dad complains about his arthritis all the time, but my mom seems to be in good health.

- Counselor OK. And thinking of their siblings, all your aunts and uncles, are there any that passed away when they were young or have any major medical problems that you've heard of?
- Patient I have one uncle – my mother's brother – who died when he was 20, when the truck he was in rolled over.
- Counselor OK, but nobody died early of illness? Just an accident?
- Patient Oh, and my grandmother's first baby died really young. They say he was just a few months old.
- Counselor And do you know why he died?
- Patient I don't know. My grandmother doesn't like to talk about it.
- Counselor Yeah, that's a hard thing to talk about, for sure. But other than that, no other children passing away at a young age?
- Patient No, not that I know of.
- Counselor Great. And what would you say your ethnic background is? What country are you from originally?
- Patient I'm Mexican.
- Counselor And how about your husband?
- Patient He's from there too.
- Counselor And switching over to his side of the family, how many brothers and sisters does he have?

**(more of the same for the husband's side)**

- Counselor So, thinking of both sides of the family, is there anyone you know of who has had three or more miscarriages?
- Patient No . . . but . . . well, it's hard to say. It's not something we talk about. I mean, I never told anyone about my second miscarriage . . .
- Counselor That's understandable. People don't always like to share that information. Anyone have babies that had physical problems that needed surgery to fix, say a heart problem, or a kidney problem or a brain problem they needed surgery for?

- Patient No.
- Counselor And is there any chance that you and your husband might be related to each other by blood? Like, that you might be cousins to each other?
- Patient No, we're not related.
- Counselor We always ask that in genetics because there are certain things that, if people are closely related to each other, there can be a genetic predisposition for certain conditions, so we always like to ask that to see if there's anything else we need to ask about in the pregnancy.
- Counselor So, I should say that every couple, no matter what your age is, no matter what your history is, we all have about a 3% chance for a baby to be born with some kind of genetic problem. And that could be anything from heart problems, to kidney problems, to a physical difference, so that's kind of the background chance that we all have no matter our health or any other factors. So we are looking to see if there is anything in your particular case that would raise that chance. And from your family history, there is nothing that I would be overly worried about, that might put you at higher risk. So that's a good place to start.
- Counselor So, like I said, to switch gears a little bit, we always meet with women who are over 35, because there are certain types of problems that babies can be born with, that the chances of that happening go up when the mother is older when she gets pregnant. And one of the things that there's a higher chance for is what we call a chromosome problem, and I'll explain what that is as we go along.
- So, have you ever heard of Down syndrome before?
- Patient No.
- Counselor No? OK, so I'll show you some pictures. I don't know if you've ever seen children whose faces look a little bit different like this, they can tend to learn things a little bit slower and need to be in special classrooms, and they can have other medical issues like heart problems as well. So, does this look familiar at all?
- Patient Hey, this picture looks just like my niece! Isn't she cute?
- Counselor OK, well, I couldn't say without seeing your niece and having a look at her medical records, but I suppose it's possible that she could have Down syndrome. And this Down syndrome is one type of chromosome problem, so I'll explain what actually causes that to happen. We women, when we get older in our pregnancies, there is a higher chance for babies to have



this condition – Down syndrome – and there’s a higher chance for our babies to have all types of chromosome problems in general.

So let me show you this picture to explain what the chances are for older moms to have babies with chromosome problems. In your age group, we’d say that there’s a one-in-70 chance of having a baby who’s born with Down syndrome. That means that if there were 70 women your age who were pregnant, one of them would have a baby with Down syndrome and the rest would have babies who do NOT have Down syndrome. That’s a bit over a 1% chance of having a child who is born with this condition, and so it’s close to a 99% chance that you would NOT have a child with Downs. The vast majority of pregnancies don’t have any of these chromosome differences, but we always talk about them because for women who are over 35, what we can do is we can offer a little more testing in the pregnancy to check and see if the baby *could* have Down syndrome or different chromosome problems.

Patient        And can you fix that?

Counselor    There’s nothing we can do to actually go in and fix any of these chromosome problems or genetic conditions. If the baby does have a chromosome problem, it’s something that was there from the very beginning, from the moment of conception, and there’s nothing we can really do to go in and fix it. Couples choose to find out whether their baby has a condition like this because, well, they might just want more information, and most of the time, they get reassurance that everything’s OK and the baby looks healthy. Other couples might want to get this information because it might change for them if they want to continue the pregnancy or stop the pregnancy, like have an abortion. I don’t know if that’s something that you and your husband have ever talked about. I know it’s a hard thing to talk about, but do you think that if you found out that the baby had Down syndrome or another more severe problem, it would change for you what you would want to do in the pregnancy? Whether you would continue the pregnancy or stop the pregnancy? Or would it not make a difference?

Patient        Does this mean that you think there’s something wrong with my baby?

Counselor    It doesn’t, no. This is something that we talk to everybody about. There’s no reason that we’re overly concerned about your pregnancy. It’s just that for everyone over 35 we talk about this because the chances are a little bit higher that the baby could have a problem. But like I said, there is close to a 99% chance that the baby will NOT have a chromosome problem, so most likely there is nothing that we have to worry about. We can do a little more testing to make sure, if that’s what you want, and that’s the next thing I wanted to talk about. There are a lot of different blood tests,

ultrasounds, and other types of tests that we can offer women in their pregnancies to see if there could be any chromosome problem.

Patient Can the testing cause a problem with the baby?

Counselor Well, yes and no. There are different types of tests. On the one hand we have screening tests, like blood tests and ultrasounds, and these don't harm the baby at all; there's absolutely no risk to the pregnancy in doing those. Ultrasounds and blood tests, they don't tell us for sure, a definite yes or no answer about whether the baby has a problem or not, but they can kind of give us clues as to whether there really is a high risk of the baby having any problems or whether everything is good.

On the other hand, there are other types of tests we can do during pregnancy. We call them diagnostic tests, and that means that they do give us a 100% definite yes-or-no answer about whether there is a chromosome problem. Those kinds of tests are a little bit more invasive, meaning that we actually take a sample of genetic material from the baby. Because those are more invasive, there is a risk of causing a miscarriage if we do those tests.

All of these screening and diagnostic tests, they're all optional. Some couples choose to do all of the tests, because they really want to know a definite answer about whether their baby could have one of these conditions or not. Other couples choose not to do any testing at all, because they're either not concerned, or it wouldn't change their decision about moving forward with the pregnancy. So everyone's kind of different in terms of what tests they choose.

But to answer your question, the blood tests and ultrasound present no risk to the pregnancy, and with some of the more diagnostic, more invasive tests, there is a small chance of miscarriage.

So I know I said that, you know, there's a one-in-70 chance of a baby having Down syndrome, and overall we say that for any chromosome difference there's a one-in-40 chance. Again, that means that if we had 40 women your age who were pregnant, one of them would have a baby who would have some kind of chromosome problem. But the other 39 would not. So that's a little over a 2% chance. How does that number sound to you. Does that sound high or low? Does it sound like something you'd be worried about?

Patient I guess I always worry about my baby. I would never get an abortion, but maybe it would be good to know ahead of time if there's going to be a problem.

Counselor Sure, definitely! And some people choose to do some testing and check on the baby, just because they want a little more information and they want to be able to plan and prepare before the baby is born if there could be a problem like this.

### **Interpreter #3**

Counselor So, what we can think about next is what these chromosome problems could be, actually. I know that you said you'd never heard about chromosomes before, so I want to explain a little bit more about the genetics of all this and why there's a chance for older women to have problems when they get pregnant.

So did you ever learn anything, back in the day, in school, about DNA, or have you ever heard about anything like that?

Patient Well, I only went through the 6<sup>th</sup> grade.

Counselor OK, well, they probably didn't talk much about genetics then. We know a lot more about it now, so it's more common today for people to learn more about it in school. But really, most people don't know too much about genetics, so that's what we're here for.

I want to show you this picture. Our bodies are made up of cells, right? And inside of those cells we have all of our genetic information. And our genetic information – our DNA – is basically like an instruction manual. It's all the instructions about how everything in our body is supposed to work. It determines every trait, everything from what eye color we have, what hair color we have, how the heart works, how the brain works. It's all the instructions about how the human body works and grows and develops. And that's something that we have in every cell of our bodies, our DNA.

So if we look at what DNA actually looks like under the microscope, it's like this picture here. These are called chromosomes. So if we looked through a microscope and zoomed in really close to look at our DNA, all these little squiggly things are called chromosomes. And that's how all our genetic information is organized, on these chromosomes. If we take this picture, and we sort of line up all these chromosomes, this is the next picture that we would see. Usually for all of us, we should have 46 chromosomes in total. You can see that everything comes in pairs, like this. And we number all the chromosomes from one to twenty-two, basically by order of size. You can see that numbers 1 and 2 are the biggest and numbers 21 and 22 are the smallest. And then we have two sex chromosomes. So, women, we would usually have 2 "X" chromosomes, and men have one "X" and one "Y" chromosome. That's

the only difference between men and women – this “Y” chromosome. But other than that, men and women both have 46 chromosomes in 23 pairs.

Now, how this works is that we actually get one from Mom and one from Dad for each of them. This is why we are sort of like half our mom and half our dad, why you might have some features that look like your mom and some that look like your dad. It’s all because of our genetic information. What we should have is 23 chromosomes that come from the egg, and 23 chromosomes that come from the sperm, and then those come together and make the baby, which then has 46 chromosomes in every single cell. So the important thing for humans is that we have just exactly this amount of chromosome material – that we have exactly 46 chromosomes. If you have anything that is extra or missing – like if a person has 47 or 45 chromosomes – that can cause problems.

It’s something that happens by chance. There’s nothing you do to cause it to happen, nothing you can do to stop it from happening, but sometimes one egg cell or one sperm cell, instead of having what it should have, which is 23 chromosomes, it randomly has 24 chromosomes or 22 chromosomes. It has nothing to do with our health, but it just happens as we get older that some of our eggs have 22 or 24 chromosomes. And if that is the egg that gets fertilized and forms a baby, then that baby will have an extra or missing chromosome in every cell.

Counselor Now the types of problems that can happen when we have an extra or missing chromosome depend on which number chromosome it is. So a lot of times, if there is an extra chromosome or a missing chromosome, it will just cause a miscarriage early on in the pregnancy. With most chromosome problems, the baby just cannot really survive to be born, because it causes so many problems. So if, for example, there is an extra copy of this chromosome two, that baby will not survive because that’s just too much extra genetic material. But there are a few chromosome problems where the baby can actually survive to be born, and these are the ones we try to look for, to screen for in the pregnancy. Does that all make sense so far?

Patient I guess so.

Counselor The most common chromosome problems that occur are having an extra copy of chromosome number 13, 18, 21 or the sex chromosomes. So, the condition Down syndrome, that happens when the baby has an extra copy of this chromosome number 21, as you can see on this picture here. Instead of having 2 copies of chromosome number 21, the baby actually has 3, and that little extra chromosome is what causes the learning differences, the other medical issues that can go along with Down syndrome – it’s all because of that little extra chromosome there. So that’s

the most common one.

Other ones that can happen and cause damage are called Trisomy 18 and Trisomy 13 – the number just tells us which chromosome is extra. Those two are generally very severe and the prognosis is not so good. Babies that have an extra copy of chromosome 13 or 18 usually don't survive the pregnancy, or, if they do, they'll usually pass away soon after they're born. So those are more severe than something like Down syndrome. And they are more rare – they don't happen as often.

The other that I'll show you pictures of is that sometimes people can have extra or missing copies of the sex chromosomes. And usually those are not as severe. They can cause mild learning problems or problems with becoming pregnant later in life, but usually they're not very noticeable. A lot of people have these sex chromosome differences and don't even know that they do. Those are kind of on the milder end of things. So you can see that there's kind of a spectrum, and that it all depends on which chromosome is extra or missing what issues it could cause for the baby.

Now, there are different ways that we can check and see if the baby has any of these chromosome differences. The first thing we do is an ultrasound, and we're going to do a first ultrasound today, after our meeting. That ultrasound is going to check to see how the baby is growing, make sure everything's OK with the placenta, make sure the fluid looks good, and then they're actually going to take a picture of the back of the baby's neck. It will look like this, like this picture I'm showing you here. There's a little pocket of fluid that all babies have at this point in the pregnancy, and we take a measurement of that because we know that if there's a lot of fluid there – a condition called nuchal thickening – it means there's a much higher chance that the baby could have a chromosome problem. It's kind of an early sign of whether there could be a chromosome problem or heart problem or other rare genetic condition. That's one thing that they'll check today.

The other ultrasound we'll usually do is the 18-week ultrasound – that's the one where we can usually see if the baby is a boy or a girl. Baby's a lot bigger at that point, too, so we can see everything, head to toe. So they'll take a lot of pictures of everything and give you a lot of pictures of the baby at that point too. Usually in this ultrasound we can see if the baby has any major physical problems, so if the baby has major heart problems or kidney problems or brain problems, a lot of the times we can actually see it. So that's another good test that can give you a good idea if the baby is growing OK and everything looks good. So those are the two main ultrasounds that we do, OK?

Then there are lots of different tests you can do in addition to the ultrasound if you want to, OK? On the one hand, there are blood screening tests, which I mentioned. The newest and most accurate blood screening test that we can do to check to see if there's a chance that the baby can have chromosome problem is a blood test that we can do any time after 10 weeks in the pregnancy, and it's called Non Invasive Prenatal Testing, or NIPT for short. Basically, it's a blood test, and we could do it today if you wanted to. See, what happens in a pregnancy is that floating around in your blood there are actually tiny pieces of the baby's chromosomes, of the baby's genetic material. So what we can do with the blood test is that we can actually count how many pieces of these different chromosomes are in your blood, and does it look like there are any pieces that there's too much of or too little of. And if there is, we know that YOU don't have a chromosome problem, so we would think that maybe the baby might have a chromosome problem. So for example, if we see that in your blood there's a lot of little extra pieces of chromosome 21 floating around, then we might think that there's a higher chance of the baby actually having Down syndrome.

This blood test, this NIPT testing, is pretty accurate. It's over 99% accurate in telling us whether the baby could have Down syndrome or Trisomy 18, and it's a little less accurate in telling us about Trisomy 13 and sex chromosome differences. But basically the results of this test will either come back negative, meaning that there's a very low chance of the baby having one of those chromosome problems – not zero, but very low – or, if it comes back positive, it means that we'd be concerned and think that there's a much higher chance that the baby actually has whatever chromosome problem that is. But it still doesn't mean for sure that it does have that chromosome problem. It just means there's a much higher chance.

So that's one of the main blood tests that we would usually offer women during pregnancy at this point. Does that make sense so far, that blood testing process?

Patient H'mmm.

Counselor OK, so what do think about that as a blood screening test? Would you like to do that blood testing, or would you just like to do ultrasound?

Patient It doesn't take blood from my baby, right?

Counselor Right. It's just a blood sample from your arm – just one tube of blood.

Patient Well, I guess I could do that.

## **Interpreter #4**

Counselor OK, OK. So that will give you a good idea and some reassurance. If that test comes back negative, we would say there is an incredibly low chance of the baby having any of these chromosome problems. Again, it's not a guarantee, but we would say, OK, you're in the very low risk category and we're not worried about any of these issues.

And if it does come back as positive, like I said, it doesn't mean for sure the baby has that chromosome problem, but we would say there's a higher risk of that happening. Now, if the test comes back positive, there are more tests that we can do at that point, if you wanted to, to find out a definite, 100% answer about whether that chromosome problem is there or not. Those are the more diagnostic, invasive tests where, if we did them, there is a small chance of causing a miscarriage as a result of doing those procedures. So I'll show you a picture of what the different options are.

The first test we do, which is the earliest test, is called a CVS, which stands for chorionic villus sampling. You can see it in this picture here. This is a test we do between 10 and 14 weeks of pregnancy, and what we're trying to do in this test is to take a small sample, a small piece of the baby's placenta. The placenta is made of the same genetic material as the baby. So if we take a little sample of the placenta, we can take those cells, we grow them in a lab, and then we can actually get a picture of what the baby's chromosomes and tell you for sure whether there is an extra or missing chromosome. In this test, we either go in with a catheter through the vagina or we go in with a needle through the abdomen and take a little sample. There is about a 1% chance of having a miscarriage as a result of doing the CVS. So there's a 99% chance that it would NOT cause a miscarriage, but for every 100 women who have this test done, it would lead to a miscarriage for one. Still, that test would give you a definite answer about chromosome problems.

The other option is another test done a little bit later in the pregnancy, any time after 16 weeks, called an amniocentesis. In this one, they go in with a needle, through your abdomen, and they take a small sample of the fluid that's around the baby. And that amniotic fluid, it has the baby's cells in it – that would be skin cells and other bits of the baby's DNA – and again, we take those cells and grow them in a lab and look at a picture of the chromosomes, and then we can tell for sure if the baby actually has a chromosome problem. That test has a little lower chance of a miscarriage. We say it's about a 1-in-300 chance of having a miscarriage as a result of doing amniocentesis. That's about a .3% chance of having a miscarriage, or a 99.7% chance that you would NOT miscarry because of that, but those are risks that do exist when you do any of those invasive tests. So

on the one hand, they give you a definite answer, but on the other hand, there is some risk to the pregnancy if we do those tests.

Everyone's different in regards to whether they'd want to do these more invasive tests. What are your thoughts? Do you think that if a blood test came back positive and said that there was a higher risk, would you want to do one of these more invasive tests, or do you think you wouldn't want to?

Patient I don't know. If you put a needle in there with my baby, how do you make sure that you don't stab my baby?

Counselor Great question. While we're doing any of these procedures, we're always looking on ultrasound to make sure that the needle doesn't go anywhere near the baby, and to make sure that the baby's not moving anywhere too close to the needle. The doctors who do these procedures have done many, many of them. They are very experienced in doing them, and they are always looking on an ultrasound to make sure that the needle is not hurting the baby.

Patient Do I need to make a decision about this right now? I think I have to talk with my husband.

Counselor Yeah, absolutely, that totally makes sense. No, you don't need to decide about this right now. If you want to, today we can start by doing that ultrasound and we can do that blood screening test that I talked about. That's a good way to start. Because if that test comes back negative, then, like I said, we would say that there is an incredibly low chance of the baby having any problem.

You could still choose, at that point, even if the test comes back negative, to do these more invasive tests if you're worried and want a more definite answer. But you don't have to do any of these invasive tests at any point in the pregnancy. Some women want a definite answer, but others don't want any risk to the pregnancy and choose just to wait until the baby's born. So I think it's a good thing to talk to your husband about. And if the blood test comes back positive, we can still talk a lot more about what exactly it came back positive for, about what issues a baby with that chromosome difference might have, and then we can have another conversation about whether you might want to do any more testing to find out a definite answer, or whether you just want to do ultrasounds moving forward. Because I know you said that for you it wouldn't change for you what you would do with the pregnancy, whether you would continue or stop the pregnancy. So the testing would be more for your peace of mind – to say, “Oh the baby definitely does NOT have this problem,” or to say, “OK we know now that this is happening, so how do we move forward.”



And I can give you more information about the condition, make sure that you're prepared, and make sure that we're doing ultrasounds and following you closely throughout the pregnancy. So that's something to think about and talk to your husband about, but not something you have to decide today.

So today, we'll do the ultrasound first, and then we can do that blood test. The results will take about 1-2 weeks to come back. I'll call you on the phone with the results as soon as they come in, and we'll chat on the phone about whatever they are. And then based on that we'll make a plan for going forward. OK?

The bottom line is that, for you, most likely the baby is healthy and doesn't have any of these problems. But by doing the ultrasound and the blood testing, hopefully we can give you a little more reassurance that everything is looking good.

Patient I hope my baby is OK. Now I'm worried.

Counselor Well, we don't want to make you worried. We just want to make sure that you have some good information. Most of the time these blood tests come back negative, and then we're able to reassure you that the baby is healthy and that everything is looking good. And today's ultrasound will give you some good information too about the fluid at the back of the baby's neck, and just overall how baby's growing and developing. We don't want you to worry too much about anything.

Patient Well, thank you.

Counselor I have your phone number here, so I'll call you when the results come in. You have my phone number, so please feel free to call me with any questions. Or if you're chatting with your husband and he has questions, please do give me a call and I'm happy to speak with him as well, as I know he wasn't able to come with you today for the appointment.

Patient Could he come for the next one?

Counselor Absolutely! Yeah, we're always happy to have partners come in too. OK, other than that, do you have any questions? I know we talked about so much information today.

Patient Um, well, no, I don't think so.

Counselor Well, if anything comes up, just jot it down and we can always chat on the phone. So I'll walk you over the ultrasound now, and we'll chat soon on the phone.