Appendix 1: Examples of Provider Counseling Scripts

<table>
<tr><td rowspan="2">Provider 1: (female, resident)

Script: Provider discusses diagnostic testing first then offers screening as a non-invasive alternative</td><td>Pvd 1: Did you do genetic screening for Down Syndrome and Tri 18 for your last babies?
Pt A: No
Pvd1: What we offer everyone is the option for genetic diagnosis and the option for genetic screening. Genetic diagnosis is a chorionic villus sampling at about the gestational age that you are and the next couple of weeks to take a little sample of the placenta that's developing around the baby and we actually send that to the lab and ask the lab to tell us what do the chromosomes look like. That is an invasive test and carries a risk of miscarriage. When you're a little later in pregnancy we talk to you about amniocentesis if you're interested in that kind of information.
Pt A: I'm not worried about it. That's not a decision I'm going to make anyway, so.
Pvd 1: Right. So it sounds like you have a good understanding about that. The other option you have is for the screening part. Which is a combination of bloodwork that we do for you and looking at the thickness on the back of the baby's neck. We kinda put that together in a risk profile and tell you if you're high risk or low risk</td></tr>
<tr><td>Pvd 1: So, on the agenda today will be a bunch of lab work and we can talk about what you would like to do for genetic screening. So all women who come in for prenatal care are offered genetic diagnosis. Meaning, that you have the option to have an invasive procedure which is either what is called a chorionic villus sampling in the first trimester or an amniocentesis in the second trimester. Um, the amniocentesis most people have heard of. It is a needle that takes a little bit of fluid from around the baby and there are baby cells floating in that fluid so we can send them to the lab and look at the genes. And what we look for are extra copies of genes or not enough copies of genes.
Pt B: Ok.
Pvd 1: So we can diagnose a limited number of conditions like Down Syndrome, which is three copies of chromosome 21 or trilogy 13 or Trisomy 18 which are three copies of chromosome 18 or chromosome 13. 18 and 13 are conditions where life expectancy is usually not more than a year. Those babies are born with severe birth defects and generally don't live longer than a year. So, and then there are a couple of different sex chromosome conditions, like Turner's Syndrome which you may have heard of. Generally shorter women with a relatively normal life expectancy. And a couple of other less common variations where you get an extra copy of one of the sex chromosomes. If you are very worried and wanted to know for sure, yes or now, those are options</td></tr>
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	for you. What a lot of people will do, you are 23, so your age related risk of having one of those problems is very low. Pt B: Mmmhmm. Pvd 1: So a non-invasive option is to do a screening test. So since you are in the first trimester, we can do what is called a first trimester screen. And this involves an ultrasound that measures the thickness of the back of the baby's neck and blood work that you have done with your other routine labs. Then we put all of that information together with your age and it comes back as no increased risk for Down Syndrome or increased risk for Down Syndrome and Trisomy 18 and then based on that information if you are at increased risk, then we can send you for one of the invasive procedures if you wanted to. Does that sound like something you would like to have done? Pt B: Probably the non-invasive.
Provider 2: (female, resident) Script: Reviews process of ultrasound and blood work, describes results as "doesn't say yes or no", discusses patient's baseline age-based risk, emphasizes that screening is optional	Pvd 2: The other optional test is a screening test to look for risk of Down Syndrome. Um, or one of the most frequent causes of mental retardation. The screening test is a combined test so one part of it is an ultrasound where they measure the thickness of the back of the baby's neck. Pt C: mm huh Pvd 2: And the second part is where they actually draw your blood on that same day and look for 4 different hormone levels. And then they add together those two results and tell you the risk of your baby being affected by Down Syndrome. So it doesn't say yes or no your baby does or doesn't have this disease, but it lets us know whether there's a slight increased risk of your baby having it. Again the risk for that is very low – you're a young person, the risk goes up after age 35 and continues to go up after that. But at your age the chances of it are very very low. But it's another optional test and we can do that if that's covered by insurance to and you're interested in it. Pt C: Would you recommend it just in case for me? Pvd 2: I mean it's totally up to you.
	Pvd 2: The other optional test is the test for Down Syndrome. It tells us whether your baby is at increased risk for Down Syndrome or not. That is the most common cause of mental retardation. Pt D: Mmmhmm [understands] Pvd 2: What they do for the test, is during a certain time frame, so between 11-13 weeks, so they wouldn't be able to do it today, they would do it, depending on how far along you are when we get your first ultrasound, they would probably do it at your next appointment after that. They draw blood work from you again, and do an ultrasound where they measure the thickness of the back of the baby's neck and using those things, they determine whether your baby is at increased risk of having

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	Down Syndrome. So again, it doesn't say yes, your baby has Down Syndrome or no, he or she doesn't. It just says, hmm, there are a few things that are concerning for increased risk we would recommend further testing. Now again, you are at a very low risk because you have no family history, and because of your age. Age is the most, the biggest risk factor for Down Syndrome, so. Another thing that you are at very low risk for but these are optional tests that we offer everybody.
Provider 3: (female, nurse practitioner) Script: reviews process of ultrasound and blood work, describes results as "increased risk" for Down Syndrome, discusses referral to genetics and/or amnio if screening is positive.	Pvd 3: Alright. So um, there is some early genetic testing that we can offer you at this part of the pregnancy. Do you remember getting any of that with your first baby? Pt F: Yes I do. Pvd 3: Ok, so at 11 or 12 weeks and you are at 7 weeks now, they do something called a first trimester genetic screening, where they do an ultrasound and a blood test to see if you are at an increased risk at all for having a baby with Down Syndrome. If it does show there is an increased risk we would have you talk to genetic counselors and possibly do a confirmatory test like amniocentesis where they draw the fluid from the baby and test. Pt F: Ok.
	Pvd 3: There are genetic screenings we can do this early in pregnancy. Something called a first trimester genetic screening. They look specifically for your risk of having a baby with Down Syndrome. It does not diagnose a baby with Down Syndrome. It does not let us know for sure yes/no, but it kind of helps us identify those that maybe at risk and who may need additional counseling from genetic counselors or possibly offering amniocentesis. Pt H: Ok. Pvd 3: Some people really want to know anything and everything that could be going on and could be wrong. Some people don't want to know any of that stuff. Pt H: I want to know Pvd 3: So we will order that. Part of that is an ultrasound and a blood test and that is usually done about 11-13 weeks. So it will be in the next few weeks that would happen.
Provider 4: (female, nurse midwife) Script:	Pvd 4: We offer an ultrasound between 11 and 13 weeks, it's called a first trimester screen. They date the pregnancy, they look at the back of the neck, because Down Syndrome babies have a big fold, and they do a blood test, from your arm not the baby. They calculate for Down Syndrome and Trisomy 18. Are you interested in having that done? Pt G: yeah Pvd 4: OK.

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Very brief, reviews screening process, clarifies that testing is non-invasive, describes risk as "calculates for Down Syndrome and Trisomy 18"	Pvd 4: We order a test called a first trimester screen. It's an ultrasound and a blood test, not from the baby from your arm. They calculate for Downs and Trisomy 18. It's done between 11 and 13 week. Did you want to have that done? Pt G: As long as it's drawn from me, I don't want … Pvt 4: Yeah It's non-invasive for the baby Pt G: Yep, that's fine Pvd 4: I mean you can ask for CVS or amnio if you want it, most people don't chose for it Pt G: No, no Pvd 4: There's about a 1 in 1000 miscarriage risk.
Provider 5: (male, OB attending) Script: Very brief, no explanations	Pvd 5: OK, genetic stuff. So do you want to be tested, your baby tested for genetic stuff like Down syndrome, trisomy, all that stuff? Pt H: Yeah Pvd 5: OK
	Pvd 5: We are going to do an ultrasound. Do you want genetic testing like for Down Syndrome and stuff? Pt H: Yeah you can do that Pvd 5: OK, so we will do that

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