



Connecting the World to Fight Twin to Twin Transfusion Syndrome
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THE TTTS FOUNDATION'S 15 MOST IMPORTANT QUESTIONS AND EXPLANATIONS

Confirm at initial ultrasounds (preferably by 10-16 weeks)

1. Is the placenta monochorionic?

TTTS only occurs in identical twins with a single, shared monochorionic placenta. Placental type can be determined as early as 6 weeks of pregnancy.

2. Are the babies the same gender?

Monochorionic twins are identical, so by definition they should be of the same sex, and will carry a risk for TTTS.

3. Can you see the dividing membrane?

The 'dividing membrane' is formed by the two amniotic sacs of the twins meeting in the middle of their placenta. A thin, wispy membrane confirms that the twins are monochorionic. A thick, easy to see dividing membrane is seen when the twins have separate placentas. Inability to see the membrane at all does not always mean same sac (monoamniotic) twins. For instance, in TTTS the membrane may be 'shrink wrapped' around a donor baby who lacks amniotic fluid, and further pressed around the donor by the excess fluid in the recipient.

4. Is the placenta implanted on the anterior or posterior surface of the womb?

Laser surgery may be performed on placentas in either location, but the anterior location presents more challenges. Depending on the doctor's technique, the twins will have a greater risk of still having open connections with anterior placentas. Placentas that wrap around 3 surfaces (anterior, fundal, and posterior) may also be difficult to operate upon.

5. Do the twins' umbilical cords each have the normal 3 blood vessels, or does one of them have 2 vessels?

Identical monochorionic twins should, by definition, be the same in every way. It is not uncommon for the twins (both TTTS and non-TTTS) to share their single placenta unequally. This is the most common reason for size differences, which can be more than 20%. The smaller twin will have the smaller placenta, and its umbilical cord may have only 2 blood vessels in it.

6. Are the umbilical cords fully attached to the placenta?

Identical monochorionic twins can be more than 20% different in size. Similar to the 2 vessel umbilical cord, the umbilical cord may not insert into the placenta itself, but into the membranes that surround the baby and signify a smaller placental share for that twin. This is called a velamentous cord insertion.

Questions to ask at weekly ultrasounds (16 weeks to delivery)

7. What is the largest vertical pocket of amniotic fluid in each baby's sac?

In normal twins, the deepest pocket of amniotic fluid should be around 3-8cm. When the fluid is greater than 8cm (*polyhydramnios*) and less than 2cm (*oligohydramnios*), the babies have Stage I TTTS. The fluid level differences are distressing to see, but are the findings most likely to change with treatments such as horizontal rest and nutritional supplements. You can determine the severity of TTTS to some degree, by watching what these numbers are, and how much they vary from the normal range. This information can help you to know when treatment may be needed and why, and gives you a tool to help make these decisions.

There are varying opinions as to the number where an *amniocentesis* should be done. Some experts are wary about putting a needle into the uterus, there are some risks, and so it should be done for a good reason. In TTTS pregnancies genetic abnormalities are extremely rare, so it does not make sense to do an amniocentesis for genetic reasons alone. It may also not make sense to do amnioreductions of small volumes (less than a liter), which is often the case if the deepest pocket measures 8-9cm or less. In higher stages of TTTS (III-IV), placental laser surgery is becoming the preferred treatment. Here the excess amniotic fluid is actually required to perform the operation, and should not be removed until the surgery itself. TTTS after the laser cutoff (over 25 weeks of pregnancy) will be treated with amniocentesis when necessary.

8. Can you see the urinary bladder of the donor baby?

The baby's bladder is visible on ultrasound when it contains urine. Urine is the main source of amniotic fluid. If it cannot be visualized within 30 minutes, or if the donor baby has no or little amniotic fluid, its blood volume may be too low (from transfusion into the recipient) to perfuse the kidneys enough to urinate. Recipients always have larger than normal bladders in TTTS. If the ultrasound finds a visible bladder and a 2cm or more pocket, this is much better news for the donor. These findings will help give you some perspective on the donor's status and the seriousness of TTTS.

9. What are the weights of the babies in grams? (every 2-3 weeks)

The relative size differences between monochorionic twins with TTTS (or in general) are best calculated with grams (typically 3 digits) rather than ounces (3 digits rounded to 1 or 2). The percent difference is calculated by taking weight difference in grams, and dividing that number by the weight of the larger baby. If the weight discordance is 20% or more, it is considered significant. The most likely cause of the discordance in monochorionic twins is unequal sharing of their single placenta. The smaller a placenta portion, the less nutrients are delivered to that baby. Small placentas are often associated with two vessel or velamentous umbilical cords, and Doppler flow abnormalities. Since the twins' shares of the placenta are fixed from the beginning of the pregnancy, and cannot be improved upon, nutritional supplementation and horizontal rest may help maximize the supply of nutrients to the smaller twin and help it thrive.

10. Are the Doppler ultrasound studies normal for both babies?

The Doppler ultrasound demonstrates how blood is flowing through the umbilical cords and placentas of the babies. It shows how well their hearts are pumping the blood by color (similar to taking a blood pressure which uses sound to determine systolic and diastolic numbers). In TTTS, Doppler is used to study blood flow through the umbilical cords, through the middle cerebral artery to detect anemia in the donor, and in and around the recipient's heart to detect stress or heart failure.

Common abnormal Doppler studies in donor twins include *absent diastolic flow* in the umbilical cord (blood moves forward only when the heart is contracting), and *reverse*

diastolic flow in the cord (blood moves back toward the heart when the heart relaxes). These studies are influenced by both the size of the transfusion and smaller sizes of a twin's placenta share. Reverse diastolic flow is much more dangerous, and requires urgent decision making regarding laser surgery or delivery, if feasible at the gestational age. Doppler studies are considered a routine part of monitoring complicated monochorionic twin pregnancy from about 15 weeks onward.

11. Is the heart of the recipient baby thickened or enlarged?

When the recipient baby's cardiovascular system is overloaded by a transfusion from the donor, it will show thickening and an increase in size. Here, laser surgery is the only option to stop the transfusion and reverse these TTTS signs (considered stage III). Hearts that are considered 'in failure' are also enlarged and thickened, but they are also noted to be poorly contracting. These findings are reversible after laser surgery.

12. Does the recipient baby have any signs of hydrops?

Eventually a transfusion-related severely stressed heart will fail, and the baby's body fills up with water (edema) to become hydropic. This is stage IV TTTS. Hydrops is reversible only with laser surgery. Stage IV TTTS babies can survive and be healthy, even after having hydrops, with proper treatment.

13. How long is my cervix by ultrasound, and it is showing any signs of funneling or thinning?

It is now clear to us, that as much as one-fourth of all the lost babies, as well as babies who survived with disabilities after TTTS, did so because of problems (i.e., abnormal shortening) with the mother's cervix. Doctors only began routine measurement of the mother's cervix in multiple pregnancy in 2000. A normal cervix should be more than 3.5cm long without signs of *funneling* (opening of the upper cervix closest to the baby, rather than at the vagina). A short cervix (< 3.0cm), especially with funneling, is called *cervical insufficiency* and almost ensures a premature delivery. Cervical insufficiency can be fixed by shoring up the cervix with a stitch (*cerclage*). Cerclage is performed in some centers in TTTS cases up to 25 weeks, and hospitalization for the duration of pregnancy if it is after 25 weeks.

A word of caution: there are doctors and centers that do not perform cerclage under any circumstances, for whatever reason, so be sure to ask what they do if your cervix gets short under their care. Conversely, there are other doctors who are convinced that they have had better outcomes and healthier babies for their TTTS patients, since incorporating cervical ultrasound, and cerclage when necessary, to their TTTS treatment protocols. So, it is crucial to have your cervix looked at every scan since increased amniotic fluid adds to the burden on the cervix. You should always have the cervix checked immediately before traveling to another center (especially by air) for treatment.

14. Is the smaller baby growing at the same rate?

When monochorionic (single placenta) twins are 20% or more different in size, it is considered significant. The most likely cause for this discordance is unequal sharing of the placenta. Although a size difference can be detected even in the first trimester, this difference can become extreme ($\geq 40\%$) by mid pregnancy in cases of extreme unequal sharing of the placenta (e.g., the smaller twin has less than 25% of the placenta). However, in the third trimester the babies are having their greatest weight gain, which must be supported by a normal placenta and supply of nutrients from the mother. A twin can actually 'run out of placenta,' so monitoring of their rate of growth and difference between their weights is crucial. When a monochorionic twin stops growing, the babies need to be delivered (i.e., better off out than in) or this baby will become harmed. The monochorionic placenta can be analyzed after birth to determine the twins' relative shares.

15. What is the fundal height measurement?

Doctors have long used a centimeter tape to measure the distance from the top of the public bone to the top of the pregnant uterus. In a singleton pregnancy, height in centimeters should equal the weeks of gestation, and then grow appropriately at subsequent visits. In normal multiple pregnancy, roughly 3 to 4cm is added to the number of weeks. This test can be used to find babies that are not growing enough (a low value indicates intrauterine growth restriction – IUGR), or growing too much (like babies of mothers with gestational diabetes). In monochorionic twins at risk for TTTS, an abnormally high fundal height value may be the first (and most common) sign of TTTS – *polyhydramnios or too much amniotic fluid*. It can be especially important for women having a difficult time getting ultrasounds weekly, or not being told the largest vertical pocket at the ultrasounds they have. You can get this measurement from a qualified nurse or midwife, if they are the only ones available to you. When TTTS is diagnosed, ultrasounds are then used in lieu of fundal height, because the scan provides more specific information on the babies and mother's cervix.