



Connecting the World to Fight Twin to Twin Transfusion Syndrome

411 Longbeach Parkway Bay Village, Ohio 44140 800-815-9211 tttsfoundation.org

**THE TWIN TO TWIN TRANSFUSION SYNDROME FOUNDATION'S
TTTS FACT SHEET**

- Twin to twin transfusion syndrome (TTTS) is a disease of the placenta (or afterbirth) that affects identical twin pregnancies with normal, healthy babies.
- TTTS affects identical twins (or higher multiple gestations), who share a common monochorionic placenta, at any time in the pregnancy.
- The shared placenta contains abnormal blood vessels, which connect the umbilical cords and circulations of the twins. As a result, one baby, the recipient, receives more than normal amounts of blood and his cardiovascular system becomes overloaded. The recipient then produces too much amniotic fluid, the first sign of TTTS and is at risk for heart failure. The other baby, the donor, receives less than normal amounts of blood and becomes anemic. The donor baby produces little to no amniotic fluid. The donor is also at risk for heart failure. There is a range of severity to TTTS.
- The common placenta may also be shared unequally by the twins, and one twin may have a share too small to provide the necessary nutrients to grow normally or even survive. You don't know what the placental share is until the babies are born and a pathologist can test the placenta. If the fluid is normal in the sacs, the cords are fully attached and have 3 vessels in them, the only other reason for a size difference of more than 20% in the twins is unequal placental share. Often, TTTS and placental share both play a role in monochorionic pregnancies.
- The events in pregnancy that lead to TTTS - the timing of the twinning event, the number and type of connecting vessels, and the way the placenta is shared by the twins are all random events that have no primary prevention, is not hereditary or genetic, nor is it caused by anything the parents did or did not do. TTTS can happen to anyone.
- There is tremendous hope for babies diagnosed with TTTS. However, The TTTS Foundation is fighting for pregnant mothers to get early ultrasounds in the first 3 months to determine chorionicity (is there one placenta or 2?) If there is 1 placenta, there must be weekly ultrasounds from 16 weeks through birth of the babies to scan for symptoms of TTTS and placental share problems. Treatment is available to save the babies. Care needs to be in the hands of a maternal-fetal specialist to get catch the signs early.

- **Based on 2005 USA National Center for Health Statistics** (4,138,349 total births), the rate of multiple births per year is now 1:30 (3.4%), or approximately 139,816 twins or higher multiples.
- The majority of identical twins share a common (monochorionic) placenta, and of these approximately 15% go on to develop TTTS.
- By extrapolating the number of expected identical twins (about one-third) from annual multiple births, and the number of twins with monochorionic placentas (about two-thirds), and from these the number thought to develop TTTS (about 15%), there are at least 4,500 TTTS cases per year in the U.S. alone:

**139,816 X .33 X .66 X .15 = 4,568 cases of TTTS per year in U.S alone.
(involving 9,500 or more babies)**

- Since spontaneous pregnancy loss (spontaneous abortion) and pregnancy terminations (elective abortions) that occur prior to 20 weeks go uncounted by the C.D.C., our estimate of TTTS cases may be very conservative.
- Although infertility treatments have increased the rate of multiple birth, they have not diluted the expected incidence of identical twins even though multiple embryos are often produced and implanted. Studies show a higher rate of identical twins (up to 20 times with IVF) in women having these treatments than occur naturally.

There is approximately a 1 in 1000 chance of having TTTS in any given pregnancy.