

# Twin to Twin Transfusion Syndrome (TTTS)

Twin-to-Twin Transfusion Syndrome (TTTS) is a rare complication of a twin (or higher multiple) pregnancy. It occurs when two or more fetuses share a common (monochorionic) placenta and blood from one twin is being diverted into the other twin. One twin, the 'donor' twin, is small and *anaemic* (with too few red blood cells), the other twin, the 'recipient', is large and *polycythemic* (has too many red blood cells). *Red blood cells contain haemoglobin – which carries oxygen and nutrients to the baby's cells and organs.*

The lives of both twins are endangered by this condition.

## Causes

The causes of TTTS are not known: it is not thought to be hereditary or genetic and affects roughly 1 in 1000 pregnancies. The events in pregnancy that result in TTTS are all random, and are not caused by anything the parents did or did not do. And, it can happen to anyone.

## About TTTS

Other names for Twin-to-Twin Transfusion Syndrome are: Feto-Fetal Transfusion Syndrome (FFTS) and Twin Oligohydramnios-Polyhydramnios Sequence (TOPS). TTTS has high morbidity (causes severe health problems) and high mortality (causes death) - severe TTTS has a 60-100% mortality rate.

## Chronic TTTS

This form of TTTS usually occurs between 12 to 26 weeks, but can happen anytime during the pregnancy up until the latter stages. The earlier in the pregnancy TTTS occurs, the more serious the disease because the babies are immature and cannot be delivered. As well, the babies will have a longer time to be affected by the TTTS and without treatment, most babies will not survive, or if they do will be handicapped (usually cerebral palsy).

## Acute TTTS

This type of TTTS occurs very suddenly, often during the last trimester or even at birth. Twins with acute TTTS usually have a better chance of

survive because of their gestational age, but may be handicapped.

## What actually happens in TTTS?

Identical (monochorionic) twin fetuses share a single placenta and sometimes the blood supplies from the placenta to the twins can become connected, so that they also share blood circulation. Each fetus still uses its side of the placenta, but the blood vessels connecting the twins allow blood to pass from one twin to the other:

depending on the number, type and direction of the shared blood vessels (anastomoses), blood can be transferred unevenly from one twin (the "donor") to the other (the "recipient").

Problems in the donor twin from the reduced blood supply include decreased blood volume (which causes slower than normal growth and development) and poor urinary output, causing *oligohydramnios* (little or no

*Continued on page 22*



Byron Ryman is three times bigger than his twin Lincoln, as a result of TTTS (bear in mind that these guys are identical twins!).

Born 11 weeks premature, the babies were given a slim chance of survival, with Byron weighing 3lb 6oz, (1531gm) and Lincoln, only 1lb 2oz (510gm). However, thanks to the care of the dedicated staff at the Royal Hospital for Women in Sydney, both boys not only survived, but thrived!

Photo from: [www.dailymail.co.uk](http://www.dailymail.co.uk)

amniotic fluid) – since the source of amniotic fluid is the baby’s urine.

The blood volume of the recipient twin is increased – they become overloaded with blood. This can strain the fetus’s heart and eventually lead to heart failure – and the recipient also has a higher than normal urinary output, which can result in excess amniotic fluid (polyhydramnios).

This increased amniotic fluid can result in premature birth because of increased pressure on the cervix. This is a further threat to both twins

## What are some of the Symptoms of TTTS?

- ✧ Identical twins or higher multiple pregnancy including a set of identicals
- ✧ Excessive amount of amniotic fluid (Polyhydramnios)
- ✧ Sudden change in mother’s weight
- ✧ Swelling of Mother’s body
- ✧ Premature contractions
- ✧ Bleeding

## How is TTTS detected?

TTTS is detected through ultrasound, (sonogram). It is critical that you have routine ultrasounds during your multiple pregnancy, and that you look and ask about differences in weights of the babies or oedema in one or both babies.

## What is the treatment for TTTS?

Information about available treatments vary. There is a consensus that complete bed-rest for the mother, coupled with improved intakes of protein (generally in the form of protein shakes such as *Boost* or *Ensure*), is very helpful.

There are a number of different therapies used to treat TTTS, with varying rates of success:

- ✧ **Serial Amniocentesis or Amnioreduction** - periodically draining amniotic fluid from around the recipient twin to reduce the pressure of the amniotic fluid. This treatment has limited success when performed early in pregnancy as it increases the risk of premature delivery.

- ✧ Surgery during pregnancy called **Fetoscopic Laser Ablation**. Using fetoscopy (more about this below) the surgeon finds the connecting blood vessels and uses a laser beam to coagulate the blood in these vessels, blocking them. It is only performed in a few hospitals worldwide. The overall survival rate of this procedure is 50-60%, with a 75% chance that at least one twin will survive. **Selective Fetoscopic Laser Photocoagulation**, is similar to the procedure described above, and is now available at National Women’s Hospital in Auckland.

*Fetoscopy is an endoscopic procedure during pregnancy to allow access to the fetus, the amniotic cavity, the umbilical cord, and the fetal side of the placenta. A small (3-4 mm) incision is made in the abdomen, and the endoscope is inserted through the wall of the abdomen and uterus into the amniotic cavity. Fetoscopy allows interventions such as a biopsy or laser occlusion [as described above] of abnormal vessels. (Wikipedia).*

- ✧ **Septostomy** - this treatment is fairly new, and can be done with with amnioreduction, or by itself. It involves creating a small hole in the amniotic membranes between the twins with the amnioreduction needle. The hole allows the two amniotic sacs to equalise their fluid levels. Early research findings have been positive and many centres in the UK now perform this treatment.
- ✧ **Selective Feticide** involves causing the deliberate death of one fetus, in the hope of providing a better chance to the other. This is not meant to be cruel: sometimes in severe cases it is the only way to prevent the loss of both twins.

None of this sounds very positive does it? The TTTS Foundation goes to great lengths to promote the effectiveness of bedrest, cervical checks and improved nutrition, as a successful treatment for TTTS.

## Bedrest

Due to the polyhydramnios (the excess amniotic fluid from the “recipient”

twin), the mothers uterus is enlarged way beyond what it would usually be, even for a multiples pregnancy. This means that she has a very high risk for premature labour.

Bedrest is important because it helps reduce pressure to the cervix and prevent premature labour, whereas upright positioning adds pressure to the cervix and should be avoided. Bedrest in this situation means the mother “lays on her left side, on the couch, in bed, in a recliner, outside on a lawn chair, on the floor with her kids” (TTTS Foundation).

## Cervical Checks

The Foundation recommends checking the cervix via ultrasound and putting in a cerclage (see below) if needed, and that this will save as much as 25% of TTTS babies. They stress the importance of the cervix being checked every specialist visit, by ultrasound.

**Cervical cerclage (tracheloplasty)** is used for the treatment of cervical incompetence, a condition where the cervix has become slightly open and there is a risk of miscarriage because it may not remain closed throughout pregnancy. Usually this treatment would be done for a woman who had suffered one or more miscarriages in the past, in the second trimester of pregnancy. The treatment consists of a strong suture being inserted into and around the cervix early in the pregnancy, usually between weeks 12–14, and then removed towards the end of the pregnancy when the greatest risk of miscarriage has passed. (Wikipedia)

## Nutrition

The TTTS Foundation stresses the importance of increased protein and calories when a mother is pregnant with multiples, and especially if diagnosed with twin to twin transfusion syndrome. The Foundation website quotes Dr. Julian De Lia who has investigated the nutritional aspects of TTTS. He recommends that, as well as their meals, a mother with TTTS drink 3 cans of Ensure each day—often by mid-pregnancy, mothers with TTTS are anaemic and have severely low levels of protein in the blood

*Continued on page 26*

birthday.

Over the next two years Locklan did amazingly well, with a few stints in hospital here and there, and a lot of help from the occupational and speech language therapists. He has become the most loving, creative, cuddly 3½ year-old boy, who adores his big brother and twin sister. We are truly blessed as parents, and as a family, to have Locky in our lives. Locky has one, maybe two, more open heart surgeries

coming up in the next few years. His doctors are extremely pleased with his progress, and feel he will do well in his future operations.

**So, to all those parents out there with children with heart conditions, hang in there!! Your journey with your child maybe bumpy, but every fear and every tear is worth it when you look into your child's eyes. Know, that no matter how hard it is, it is all worth it in the end.**



A very healthy Locklan, with Aaja, both aged 3½

## Twin to Twin Transfusion Syndrome (TTTS)

from page 22

(hypoproteinemia), which in turn may worsen the effects of TTTS in the babies.

And this quote from their website:

We have seen nutritional therapy and rest help many women. Not only do they begin to feel better, not being malnourished anymore, but in some, the signs of the TTTS go away! Nutritional therapy has helped avoid laser surgery or other treatments. Mothers also feel immediate relief that there is something they can do right away to help their babies. (TTTS Foundation)

This is illustrated in the story, next. Many of the websites listed at the end of this article have lots of similar stories from parents.

I began drinking three protein drinks a day and also added soy milk to my diet. My Obstetrician and I were relieved to see that Baby A actually had more fluid in the amniotic sac this time. Each subsequent ultrasound showed that although Baby A always had less fluid than Baby B, it never returned to the drastically low level seen initially. I remained on bed rest and continued to drink three protein drinks a day for the remainder of my pregnancy. Kate and Elise are now almost 8 months old and are wonderful, healthy babies. Every day I look at them and their big brother David and count my blessings. (TTTS Foundation)

The Foundation recommends that parents refer their midwife and doctor

to this website – this and other helpful websites are listed next.

### How do I find more information about TTTS?

Research into this syndrome is ongoing and medical practices change quickly. For the most up-to-date information, check out these websites:

- ✧ <http://www.tttsfoundation.org/>  
The American Twin to Twin Transfusion Syndrome Foundation website - informative, comprehensive and useful information in plain language (not medical jargon) about pretty much everything to do with TTTS.
- ✧ [www.twin2twin.org](http://www.twin2twin.org) The UK Twin to Twin Transfusion Association website, with more comprehensive information in plain language.
- ✧ [www.twinhope.org](http://www.twinhope.org) Twin Hope Incorporated was the easiest to read and understand. Lots of information on bedrest (home or in hospital), including suggestions for things to do when on bedrest and how to set up your bedrest area (so you don't go batty!). It also has lots of links to other websites with information about TTTS.
- ✧ [www.tttsmd.org](http://www.tttsmd.org) The International Institute for the Treatment of Twin to Twin Transfusion Syndrome, again with great information.

### Comment

After reviewing these websites there was a common theme that I believe people expecting twins need to know about:

1. Parents who are diagnosed with this syndrome need to immediately inform themselves of the available treatments, how often they are done and correct monitoring etc and pressure their midwife or specialist to find someone to provide the treatment.
2. And to then keep applying pressure to ensure that proper treatment continues. There are things the mother can do, and there are treatments: this is not a situation where "nothing can be done!"
2. Do not be fobbed off if your symptoms worsen - seek urgent medical treatment.

One couple in the UK with TTTS ([http://twin2twin.org/jackies\\_story](http://twin2twin.org/jackies_story)) were told that nothing could be done for their twins, but researched the problem themselves and obtained the treatment they needed, and one twin survived.

All the websites contain similar stories (often with both twins surviving) because parents wouldn't accept that there was nothing that could be done!