TWIN-TO-TWIN TRANSFUSION SYNDROME: PARENTS' STORIES

Tamba

TWINS & MULTIPLE BIRTHS ASSOCIATION

MESSAGE FROM TAMBA

In recent years, there have been steady improvements in our understanding of Twin to Twin Transfusion Syndrome (TTTS) and much greater clarity in how best to care for patients and babies. In tandem with these developments, our families highlighted the need for additional information and support, reporting that all too often they felt that were left to fend for themselves at what can be a very emotional and worrying time.

Thanks to the fundraising efforts of parents who had babies with TTTS, and support from the James Tudor Foundation, we have been able to produce this collection of parents' inspiring stories, as well as a new parent guide and set up a peer to peer support network of parents who have experienced TTTS who offer support online via the Facebook:Twin to Twin Transfusion Syndrome Support Group or by phone on 01483 304442.

If you would like clinical information and guidance then you should in the first instance speak to your own medical team. You can also contact our sister charity, the Multiple Birth Foundation, who are listed at the back of this booklet along with other helpful organisations. We sincerely hope that you benefit from this additional support, but please do keep feeding back to us with your thoughts and ideas.

Once again, our sincere thanks to all those families that have supported our work, either through fundraising or through the feedback of their own experiences. Whilst there is still much more to be done, with your help we hope to continue to improve our families' experiences for many years to come.

Best wishes,
Keith Reed, Tamba CEO and
Dr Erika McAslan Fraser, Author of TTTS: A Guide for Parents

Please note that each TTTS pregnancy is very different. The positive stories in this guide are included at our parents' request so you do not have to search the internet for real life examples. Your experience may be completely different and your medical team will be best placed to explain possible outcomes and challenges.

JOSHUA AND MATTHEW'S STORY

BY GEOFF AND CHRISTY SISEMAN

Our first scan was at 12 weeks. The sonographer immediately told us we had 'two for the price of one'! She referred us to a consultant there and then. The consultant told us that as we had identical twins, it would be a high risk pregnancy and that there was a possibility of complications. She explained that we would have far more scans and check-ups than a standard pregnancy. She booked us in for our next scans at 16 weeks, 18 weeks, 20 weeks and 22 weeks and she also coordinated follow-ups with consultants.

All was fine until we went for our 20 week anomaly scan and we thought our biggest decision at that point was to find out if we were having boys or girls! As she scanned the babies, she said there was quite a difference in size. There had been a slight difference two weeks ago, but now the difference in size had become quite significant and this could be an indication of Twin to Twin Transfusion Syndrome (TTTS). After the scan, the consultant explained to us what TTTS was and we understood that it meant our babies lives were at risk. She said she would need to refer us to Kings College Hospital to see the experts who would confirm for sure that we had TTTS.

In SCBU - Josh on left, Matthew on right with feeding tubes

Christy with Joshua (on left) and Matthew (on right)

Kings confirmed that we did have severe TTTS and qualified for laser surgery. The doctor told us that our twins each had a 30% chance of survival and the highest risk at this stage was perishing during surgery or miscarriage following the procedure, most likely within the first week. We had to sign a disclaimer that removed all blame from the hospital if the procedure failed and our babies died. I was given three forms of painkiller: a suppository, an oral, and a local anaesthetic, but the tube which was forced through my skin was fairly large (it had to be big enough to get the laser and a camera though). It was fed into the fluid sack that the biggest twin was in and we were able to watch on a screen as he moved the camera round. We saw both our babies from the inside which is a view most parents don't get to see!

We also watched as he severed the blood vessels that joined our twins. There were 12 in our case and one of them was a very large one. He was very good at trying to put me at ease during the procedure, making jokes about the quality of the food from the hospital café and asking if I wanted him to cut the twins' toenails while he was in there! His assistants then drained 1.5 litres of fluid from around the bigger twin, which made my stomach feel far less stretched! We then had to wait in a side room for a few hours, after which point they scanned me again and said the babies were still alive, although I was still bleeding from the wound, so they asked me to stay for a little while longer to make sure the bleeding stopped. It was a very long day and a very worrying time! We had arrived about 9.30 that morning and didn't leave until after 7pm!

We returned to Kings the following week and they were able to tell us that both babies were still alive and twin 1 had some fluid round him and was beginning to grow again! We were very grateful for the good news! We were warned it was likely they would arrive early. Our milestone was to get to 30 weeks and every week after that would be a bonus.

> "Try not to focus too much on the statistics and possible outcomes, take each day at a time."

We continued to have weekly scans at Kings until 30 weeks, at which point I was referred back to my local hospital. Occasionally, after that, my local hospital would ask me to go and get scanned at Kings again, as they wanted a second opinion that they were still growing ok, given the circumstances.

I was told to give up work at 28 weeks in order to rest and keep my feet up as much as possible in order to try to prevent premature delivery. I had to go to the hospital for fetal heart monitoring

twice a week from about this time. I was also given steroid injections at 31 weeks to mature the babies' lungs in case they arrived early.

At 35 weeks (on a Monday) my consultant said he thought it was time we delivered the babies and he booked me in for a caesarean the following Monday. Although Kings had said they thought all the joining vessels had been severed so it was probably safe to deliver vaginally if I wanted, my local hospital was not happy to do this.

In the week leading up to delivery, I had an appointment at the hospital to attend almost every day, which I thought was funny because I had been told to rest as much as possible! On my next appointment for fetal heart monitoring (Wednesday), twin 2's heart rate dipped so I was admitted immediately. It felt like the start of the end! The doctors decided that as long as twin 2's heart rate did not dip any more, they would continue with the plan to deliver on the scheduled date but keep me in hospital until then. We did not know it at the time but it seems twin 2 had stopped growing and this gave twin 1 time to catch up on his size! While in hospital I was given twice-daily fetal heart monitoring and all was fine until the evening before my scheduled caesarean. At 9pm, just as my husband was planning on going home for his last night sleep as a man without any parental responsibilities, my waters broke!

The hospital was very busy that night and they told my husband they wanted to move me to Brighton hospital, but he would not allow them to. I was not aware of this at the time! They told us that the babies would be taken straight to SCBU after they were born to make sure they were ok. I was surprised at this, as I had been led to believe that if they were born after 34 weeks they would not need any special care.

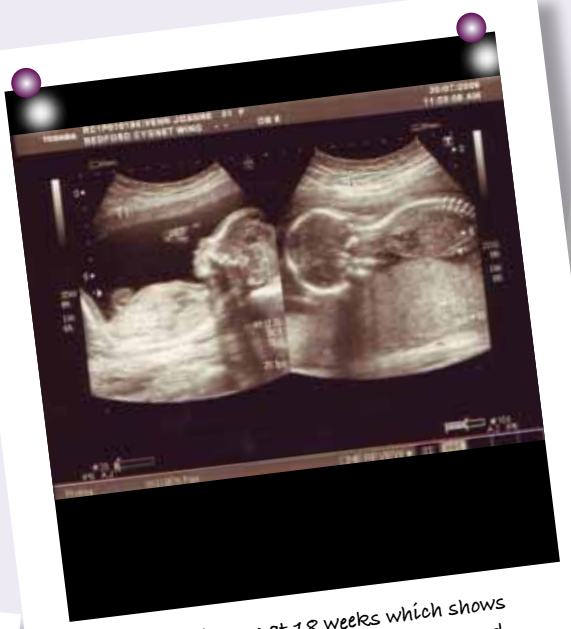
Joshua and Matthew were delivered just before midnight weighing 4.4lb and 4.6lb. There were no complications. Because there was another emergency caesarean needed in the room next door, we were allowed to hold the boys for nearly an hour after they were born. The result of this was that they needed a glucose drip when they got to SCBU because they had got cold. They spent 9 days in SCBU before coming home.

They are 18 months old now and are normal toddlers with no obvious difference in size! The advice I would give to other parents is to ask doctors for as much information as they can give you, try not to focus too much on the statistics and possible outcomes, take each day at a time and expect that they will need special care, even if it's only for a few days. It is all worth it!

Matthew on left, Josh on right aged 21 months

ASHLEY AND CAMERON'S STORY

BY JOANNE AND JASON VENN



Scan image at 18 weeks which shows Ashley, the 'stuck twin' (right) and cameron (left) with polyhydramnios

Ashley (left) and Cameron (right)

We discovered we were having MCDA twins at our 12 week routine scan. A midwife explained that this type of twin pregnancy had greater risks as they were sharing the same placenta but were in separate sacs with a clear dividing membrane. My husband and I went home and did some more research and read the leaflets we were given. We weren't aware of TTTS at this point. This was my second pregnancy, so we just took each day at a time.

At my 18 week scan, the sonographer noticed that one of the twins was stuck and had little fluid surrounding him (polyhydramnios). We got a second opinion from another sonographer and she confirmed it as Stage 1 TTTS. They immediately contacted Queen Charlotte and Chelsea hospital for a specialist referral and an appointment was made for the following morning.

Using the detailed ultrasound at Queen Charlotte's, I was diagnosed with Stage II twin/twin transfusion, with twin A (the recipient) having biometry appropriate for gestation and deepest vertical pool of 8.2cm with a polyuric bladder. Dopplers were normal. Twin B (the donor twin) had similar biometry to twin A's, but was stuck with severe oligohydramnios and a deepest vertical pool of only 1cm. No bladder was visible. Dopplers were normal. The consultant said that the appearance suggested that TTTS was of a reasonably rapid onset as there was very little growth difference between the twins. He recommended laser surgery to us and discussed the options and hospital statistics:-

1) Continue conservative management. This would almost certainly progress to a more severe stage of TTTS with greater than 90% mortality.

2) Fetoscopic laser double survival of 60% and a single survival of a further 15%, leaving at least a 75% chance of at least one baby surviving.

3) Selective termination using radiofrequency ablation.

I requested the fetoscopic laser. The procedure was then performed that afternoon. Everything went really well and I was admitted overnight. I was scanned the next morning to find it had worked!

Two weeks after the treatment the TTTS had gone, with fluid clearly visible in both sacs, both bladders visible and normal dopplers. The deepest vertical pool was 5.7cm in Twin A (recipient) and 5cm in twin B (donor). I was then scanned weekly and seen by the consultant at my local hospital due to the risk of IUGR or chronic reverse TTTS.

The care I received at the Queen Charlotte's was excellent. I should have had a 16 week scan at my local hospital (QC put this in my notes after my first visit at 13 weeks) but this was not picked up. I was told about the risk of TTTS and what it was, but NOT the symptoms. Looking back now, at 14 weeks, I had some of these. My bump suddenly appeared large and looked a funny shape and I was out of breath a lot. I do feel, if I had been given a leaflet to read by the hospital and my consultant and midwife had been more informed/aware of TTTS then it may have been picked up sooner.

> "My bump suddenly appeared large and looked a funny shape and I was out of breath a lot."

It all happened at such a fast pace, it was a lot to take in. I would advise any parents going through this to push for weekly scans and make themselves aware of the symptoms. I was one of the lucky ones. My babies thrived after the laser treatment and were born by C-Section at 36 weeks, perfectly healthy, good weights and no need for special care. My boys, Ashley and Cameron, are doing so well now; it's hard to believe I nearly lost them. Not every outcome is a sad one.

AIDAN AND CHRISTIAN'S STORY

BY MICHELLE AND CORMAC CASSELLS

One of the biggest challenges of my life was being diagnosed with Twin to Twin Transfusion Syndrome (TTTS) at 17 weeks into an identical twin pregnancy. Following a routine scan at our local hospital, we were referred to Birmingham Women's Hospital, where TTTS was diagnosed. Sadly, my husband, Cormac, and I were informed that I had a very severe case of the disease and had to make swift decisions. We were given three choices; do nothing, which would almost certainly result in losing both babies; terminate the pregnancy, which was not an option we wanted to take; or undergo laser surgery whereby blood vessels on the placenta are 'cauterised' to even up the blood flow between the babies. For us, the choice was easy and we opted for the laser surgery in order to give the babies a fighting chance.

I was admitted to hospital that evening and had the surgery at 8am the following morning, Wednesday 12th December 2007.

Aidan aged 2, with big sister Catherine

Aidan on the day he was born

RACHEL AND SARAH'S STORY

BY NATASHA FITZMAURICE

Rachel (left) and Sarah (right), 2 weeks old, just after Sarah got out of NICU

I found out I was expecting twins at 18+6 – an earlier scan had missed the second baby. The following day I was diagnosed with twin-to-twin transfusion syndrome. It was a huge shock – we had only just found out we were expecting two little girls, and now we faced the possibility that we might lose one or both babies.

The obstetrician and in particular the midwife were really wonderful and supportive. The doctor outlined our options – laser surgery, draining amniotic fluid, or doing nothing (though he made clear that without any treatment I would most likely go into labour within three weeks and lose both babies). We decided to go for laser surgery as it had the best chance of success.

At the time (July 2005), laser surgery wasn't available in Ireland, so we went to King's College in London. We had a long day of waiting, detailed scans and blood tests, the surgery was performed. I was given a painkiller but was awake throughout the procedure which took half an hour. I was then sent back to a private room to rest. Within about half an hour I felt kicking, and started crying with relief. However it was hard to be sure that I was feeling both of them and we had to wait for a scan to confirm the good news – both babies survived.

We returned home to Dublin the next day and went straight to our own hospital where a scan confirmed both babies were still doing fine. I was monitored with scans once or twice a week for the rest of my pregnancy. We had scares at 28 weeks and 31 weeks where it looked like the babies would have to be delivered due to the deterioration in the blood flow to the smaller baby, but each time it improved at the following scan. In the end I made it to

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scans to check on the progress of the surviving twin. When I started to leak amniotic fluid at 26 weeks, a possible side effect of the surgery, I was admitted to Birmingham Women's Hospital where I was told I would stay until I gave birth. The aim was to reach at least 28 weeks when the survival rate is almost 100% and I made it to 30 weeks before I was given an emergency c-section and Aidan Peter was born weighing 2lb 14oz! His brother, Christian, was subsequently cremated on March 31st 2008.

Five days after his birth, Aidan was transferred to our local hospital where he stayed for 7 weeks. He was such a fighter, requiring no ventilation or oxygen at all. He was discharged on April 30th 2008 and had just celebrated his 2nd birthday and is doing fantastically well.

It's taken me a while to come to terms with everything that has happened over the past 2 years. We lost a son but also gained a son, so it was a bittersweet pill to swallow. On top of which, we had a little girl, Catherine, who was two at the time, and she needed attention too, but dealt with mummy being in hospital and then mummy & daddy visiting another hospital on a daily basis incredibly well.

So, I'm now ready to start raising awareness for TTTS and to that end I'm undertaking a trek along The Great Wall of China in April 2011. It's a very daunting task but it's the least I can do to bring this life threatening disease to people's attention.

35+6 before the babies were delivered by planned Caesarean section.

Rachel weighed 6 lbs 4 oz and Sarah weighed 3 lbs 14 oz. Despite the fact that they were identical twins, they didn't look alike at all due to the big weight difference. Rachel spent just one night in NICU being monitored, then she was on the ward with me and went home with me on day 5. Sarah needed tube feeds and stayed in NICU/SCBU for 15 nights. We were so thrilled when she was able to come home, 2 weeks before her due date, and we were all together as a family.

Rachel (left) and Sarah (right), now 4 and a half years old

Rachel and Sarah had a shaky start in life but they never looked back. They both grew quickly and although Rachel is still a centimetre taller and two pounds heavier, the difference between them is not noticeable at all and most people struggle to tell them apart. At four and a half, they are two of the happiest and healthiest little girls you could meet. In fact they are both very tall for their age and people constantly assume they are older than they are. They are the best of friends and are looking forward to starting school in September.

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KEZIAH AND JEMIMA'S STORY

BY HAYLEY JEANS

I found out I was having twins at my 12 week (dating) scan. I was just about getting over the 'twin shock' when, following a scan at 20 weeks, an obstetric registrar mentioned that, because my twins were sharing a placenta, they were at risk of developing Twin to Twin Transfusion Syndrome (TTTS). Thankfully there were no signs of it at this point but he insisted that the twins were scanned and monitored fortnightly from then on 'just in case'.

Everything seemed to progress well until around 28 weeks, when I began to feel very tired, sick and extremely itchy. Concerned that something wasn't right, I went to the Maternity Assessment Unit at my local hospital (The University of Wales Hospital, Cardiff), where I was told that I had developed cholestasis of pregnancy. I was put on a couple of different medications to relieve the symptoms and, as a precaution, it was decided that the twins be routinely monitored three times per week and scanned weekly.

Although I knew this was sensible and in the best interests of the babies, it was difficult and time consuming, having to spend literally hours waiting in hospital every week, taking time off work and having to arrange additional childcare for my 21 month old son (Asher). The one redeeming factor was that I live on the doorstep of the University Hospital of Wales, four minutes walk to the maternity unit.

Keziah (left) and Jemima (right), 6 weeks old

At 30 weeks the various doctors and radiographers I was seeing, started to question the blood flow through the umbilical cord and by 31 weeks I was being monitored daily. None of the medical staff mentioned TTTS at this stage but they seemed to think that something wasn't quite right and suggested that I have steroid injections in case the twins had to be delivered in the next few weeks.

During the next couple of scans the fluid around one of the twins looked very low and at 32 weeks I was referred to a doctor of fetal medicine, who decided that there was little or no fluid around one baby. I was sent

straight to see the obstetrician on duty, who looked at my medical notes and said that the babies had to be delivered within the next 12 to 24 hours.

After waiting for the doctor to make some calls to arrange beds for the twins and myself, she returned to say that all the hospitals across South Wales and the West of England were full and I would have to be transferred to Birmingham Women's Hospital some two and a half hours away. I was in utter shock and disbelief that I lived on the doorstep of the biggest teaching hospital in Wales and yet had to go hundreds of miles away to have my babies delivered. I telephoned my husband, Rich, who came to the hospital immediately, and my parents to ask them to come and look after my son. Then I cried my heart out at the thought of leaving my son, husband and family at one of the most important and worrying times of my life.

I had an hour to pack a bag and then return to the hospital and was then transferred to Birmingham by ambulance, with Rich following in a car behind. We arrived at around midnight and, after being booked in, they began to try and monitor the twins' heart beats. After a couple of uncomfortable hours of trying to sit still in order for them to get an accurate trace, the nurses were happy. I was told I would be scanned in the Department of Fetal Medicine in the morning, when the doctors in Birmingham would then decide what to do.

After a very tense and restless night, an obstetric registrar came to see me and commented that 'we do things differently here to Cardiff' and that he was not sure when I would be scanned. The monitors were put on again and left on all morning. On a couple of occasions I asked a midwife when I would be scanned or when it would be decided what was happening. I was told that I would be called when they were ready.

Around lunchtime it was decided to move me down to delivery, although I was not clear why. Yet again I had to sit and have monitors strapped onto me to check the twins' heart beats. I was beginning to get very uncomfortable from sitting in the same position hour after hour and also concerned that it was now some 22 hours since staff at the hospital in Cardiff had said that I should be delivered within 12 to 24 hours. Discomfort and anxiety got the better of me and I lost my temper and demanded to see a consultant. When the consultant arrived, he looked at my notes and became even angrier than me. It appeared that as I had been an inter

Keziah (left) and Jemima (right), 18 months old

hospital transfer, I had been missed off the list to be scanned in the morning and the Department of Fetal Medicine were not aware that I was waiting!

Once the mistake was realised I was sent straight for a scan and the professor of fetal medicine confirmed TTTS and said I should be delivered immediately. The twins were delivered by emergency caesarean section straight away and my two beautiful daughters, Jemima and Keziah, were born at 4.20pm, weighing 3 pounds 14 ounces and 3 pounds 4 ounces. After a quick 'hello', the girls

> "Now 16 months old, the girls are in perfect health and not a day goes by when I don't think about how lucky they were to even survive."

were taken to the neonatal unit, where they spent five days in intensive care and then five days in high dependency.

Keziah, the smaller 'donor' baby was severely anaemic and received a blood transfusion almost straight away. Jemima, the bigger 'recipient' baby was swollen and purple with all the additional red blood cells. The neonatologists had to thin her blood down with saline over a number of days, before she was in the clear. We had a couple of scares, where Jemima's kidneys did not seem to be functioning, but the staff on the unit in Birmingham were fantastic and made us feel supported and confident throughout the time the twins spent there.

Although extremely grateful for the high level of care the twins received in Birmingham, we were desperate to get them home to South Wales. After nine days of frantic phone calls to the University Hospital, the Cardiff and the Vale Health Trust and even the Welsh Assembly, beds were found. The girls were taken by ambulance back to the neonatal unit at the University Hospital of Wales, where they spent a further five weeks in hospital. However, it was so much easier once they were just round the corner from our home, particularly as I was trying to breastfeed them as much as possible.

Now 16 months old, the girls are in perfect health and not a day goes by when I don't think about how lucky they were to even survive. Although my husband and I have some criticisms of what happened, these are mainly associated with my being transferred between hospitals.

Recalling all the people involved in the care of myself and the twins, I have so far recounted 38 midwives, 17 obstetricians, 7 radiographers, 2 doctors and 1 professor of fetal medicine, 3 anesthetists, 8 neonatologists, 9 specialist intensive care nurses, 4 ambulance crew/ paramedics, 1 medical transfer team and countless domestic and auxiliary nursing staff and porters. I can't imagine how much my girls cost the health service and how much we would have had to pay if we lived in many other countries but I will remind them when they are older!

SOPHIE AND EMILY'S STORY

BY NICK AND CLAIRE

I was really enjoying my twin pregnancy (after getting over the initial shock!) but by just before 29 weeks I was beginning to wonder how I could possibly get any bigger. I was staying in another part of the country with friends when I spent a very uncomfortable night because of pain under my right ribcage and general restlessness.

(L-r) Sophie and Emily

(L-r) Emily and Sophie

The next morning I had a small vaginal bleed and so duly went to the local hospital to be checked out expecting to be sent home reassured. I was surprised to be kept in and given steroids. The separating membrane between the twins was identified on the scan and there didn't seem to be any clear reason identified for the bleed.

Unfortunately that night I went into labour and in the early morning went by blue light ambulance to the nearest hospital with two beds for 28 weekers which happened to be our local hospital over 200 miles away!

By the time we arrived, labour had stopped. A midwife commented on polyhydramnios at a scan carried out by the on-call doctor and I was measuring 44 weeks. During that day and night I had the same pain and discomfort in my right upper abdomen and the midwives were having great difficulty picking up the heartbeat of Twin 2 who was positioned there (evidently because of the excess fluid surrounding Twin 2). It was not until the next day that I had a scan carried out by an ultrasonographer who gave us the results we dreaded.

It was TTTS –Twin 1 was motionless at the base of the uterus with the membrane stuck to her and no surrounding fluid and Twin 2 was surrounded by a large amount of fluid and her heart was under strain.

I felt absolutely sick with fear and just couldn't believe what was happening to us and our twins. I was sent back to the ward where we were told we would wait for an opinion from the local consultant with a special interest in Fetal Medicine who was presently off-site.

It was plainly not a time to be waiting and so we insisted on an immediate referral to Kings Hospital Harris Birthright Centre later that afternoon. Kings made a diagnosis of acute, severe TTTS and told us that the outlook was potentially very bleak. We were given the option of immediate delivery of two very sick premature babies or of laser surgery (not usually performed this late in pregnancy) with a 60% chance of at least one baby surviving. We were also faced with the possibility that Twin 2 (recipient) may have suffered brain damage due to the massive, rapid transfusion of blood.

It was a very difficult decision to make. We were given some time together in a small room to make a decision. It almost felt like it was happening to someone else but at the same time the possibility of not having our two babies we had hoped for was prominent in our minds. We decided to accept the laser surgery wishing it would be a success and give our babies the best chance to recover and have some more time 'inside'.

The surgery itself was painless but it required some focus to remain still for a relatively long time. It was amazing to see our beautiful babies on the inside and would have been very enjoyable had the circumstances been different. The laser separated the abnormal connecting vessels with loud 'pops' but no discomfort. The excess amniotic fluid was also drained off after the main procedure. We then waited 30 minutes and had another scan to see that both twins were still alive. I then had a patch stuck on my lower back containing medicines to prevent contractions and we were sent home with an appointment for one weeks

> "I felt absolutely sick with fear and just couldn't believe what was happening to us and our twins."

time. We were shocked at the time that we were sent home and we felt quite alone and uncertain of what the next 24 hours would hold.

We went into our local hospital each day for two days to have a heart tracing of Twin 2 to monitor her recovery. On the second day I had persistant cramp-like pains in my legs which continued throughout the day. By the late evening I was having contractions and we went into the labour ward, where my waters broke in the early hours. That morning Sophie Alice (Twin 1 donor) and Emily Rose (Twin 2 recipient) were born by emergency Caesarean Section weighing 2lb14oz and 3lb2oz respectively. They both cried on delivery which was the best sound I have ever heard.

They spent over 10 weeks on SCBU but did not require ventilation and we feel that the 48-hour period post-laser surgery really made a great difference to their condition at birth.

We feel so very blessed and grateful to the skill of the team at Harris Birthright and at Pembury Hospital SCBU to have two utterly adorable, happy, healthy 2 and a half year old girls today.

Our experience made us realise that you must be your babies' advocate and that if you do not feel that you are getting the right treatment or feel uncertain about the advice you are given then insist on seeing the consultant or on a referral to a specialist centre. It is important to be well-informed which helps you to feel confident about seeking the best treatment for your babies. We found the message boards on TAMBA extremely helpful both in terms of sharing other people's experiences of TTTS and links to appropriate sources of information on TTTS.

We feel that each extra day inside after the laser surgery counted and our experience shows that amazing happy outcomes can come out of apparently bleak situations.

“We found the message boards on TAMBA extremely helpful both in terms of sharing other people's experiences of TTTS and links to appropriate sources of information on TTTS.”

GETHIN AND IESTYN'S STORY

BY NIC AND GARETH KEYMER

At our first scan, when we found out we were expecting identical twins, we were warned that there were more risks with this pregnancy, and that I would be monitored more closely. However, we didn't really spend too much time thinking about it and certainly didn't think anything would go wrong.

When I was about 14 weeks pregnant I started to get big very rapidly, but we just put it down to the fact that I was expecting twins; this being my first pregnancy I didn't really know what was normal anyway. Unfortunately, when we went for our scan at 16 weeks, the consultant was concerned as soon as he saw me. It turned out that I was so big because I had stage 2 twin to twin transfusion already, and one of the babies (Gethin, the recipient) was getting so much blood that he was producing huge amounts of urine, making my tummy expand very quickly. The other baby (Iestyn, the donor) was so small and producing so little urine that the consultant said the amniotic sac was almost wrapped around him like cling film. We were told that things were not looking too good for our boys, especially as the increased blood supply was already having a bad effect on Gethin's heart. We were asked to come back the following week, when the decision would be made about what to do next.

Over the weekend, I was very aware that I was continuing to get bigger, and I started to have pains that felt just like contractions.

We went back to see the consultant at the John Radcliffe on the Monday, and it was confirmed that we had moved to stage 3 TTTS and surgery was needed as soon as possible. It was very quickly arranged that we would go the Queen Charlottes in London the following morning to have laser surgery.

Before the surgery was carried out, I had lots of scans to double check the situation, and it was explained to us that we would most probably lose the boys if nothing was done, and that there was still quite a high risk of losing one or both of them during the surgery or in the weeks after it. They also carried out cervical scans which showed that my cervix was being pushed open due to the pressure of the excess amniotic fluid.

Gethin (left) and Iestyn (right)

So, later on that morning, the surgery was carried out. It was done under local anaesthetic and it was not an especially painful procedure, just a bit uncomfortable when the laser and endoscope was put into the womb through my abdomen. The thing that was truly amazing was that we were able to see the video images of the boys on a screen as the surgery happened. They looked completely fully formed, just tiny, and they were keen to be on camera, which meant they kept on getting in the way of the surgeon as he tried to laser through the shared blood vessels in the placenta.

As well as the treatment of the blood vessels, one and a half litres of excess amniotic fluid was drained, and the individual amniotic sacs were cut through so that the boys shared a sac instead, enabling Iestyn to have some fluid around him at last and not be quite so shrink wrapped!

The surgeons (amazing men, the boys have their names as middle names) were very pleased when they scanned again an hour of so after the surgery and things already seemed to be improving. Gethin's heart scan was also looking more normal, and the boys were not showing any signs of distress. We were kept in overnight, and the scan in the morning showed things were continuing to improve. We were discharged, and came back once more, a week later, to Queen Charlotte's, before we were handed back to our local hospital in Oxford. For a few weeks we had weekly scans, and blood tests to check for infection, and then as things appeared to be going well it was reduced to fortnightly scans.

Although we were told that they hoped I would carry the boys until at least 30 weeks, I was completely obsessed with getting to 24 weeks, as this was the point at which our miscarriage risk from the surgery became much less likely, as well as it being the stage at which the pregnancy became 'viable'. And then in the early hours of the very day I reached 24 weeks, my waters began to leak. Within a couple of hours I was starting to have contractions, and when we got to the hospital at 7.30 in the morning we were told that I was in spontaneous labour due to infection. I was given steroids to help the boys' lungs, but we were warned that the chances of survival were not great. Just before 1 pm they were delivered naturally, with Gethin (the recipient) being the first out, and Iestyn (the donor) coming out breech 2 minutes later. Because of the success of the TTTS surgery, Iestyn had caught up with his brother's weight, but they still only weighed 1lb 8oz each. They were rushed off to the special care unit which was to be their home (and ours) for many months to come.

They turned out to be real little fighters, and despite the odds, Iestyn managed to come home a week after their due date. Two years on, apart from the fact that he is still quite small, you would not have any idea that he had such a difficult start to life. Gethin had a much rockier ride, with quite a few complications (but no problems with his heart, the laser surgery fixed that successfully), and we had to wait 6 months before we got him home. He was on oxygen at home for another 6 months, and still requires a feeding tube to supplement what he takes orally as his weight gain is poor. He also has cerebral palsy, as a result of hydrocephalus caused by a small bleed in his brain a few days after birth. It is not severe though, and he does not have any learning difficulties, just some problems with walking, but hopefully with lots of love and physio he will get there!

We will be eternally grateful for everything the consultants at Oxford did to pick up on our problems so early on and of course to the surgeons in London who gave our lovely boys a fighting chance.

WILLIAM AND ALEXANDER'S STORY

BY SARAH DEVONS

Sarah with William and Alex

On 9th April 2009 William Hugh and Alexander John Devons were born, but their story started much earlier than this…..

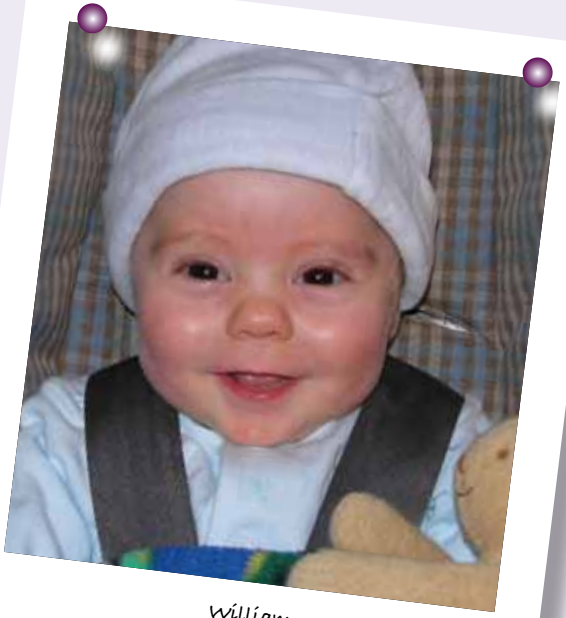
As usual I got pregnant very easily and went for my first scan at 16 weeks. It was immediately clear that I was carrying twins. As there was not a history of twins in the family we were shocked to say the least. We only wanted number three but got number four at the same time. Never mind we thought, loads of people have twins.

Little did we know how different a twin pregnancy is to a single pregnancy. Immediately we are under consultant care and because of the type of twins I was carrying, I was scanned fortnightly. My twins shared the same placenta and we were told that there was a risk of TTTS, but it was rare. I was told that if any scan showed an increase in fluid in one of the babies' sacs this was an indicator of TTTS onset. At every scan we could see a minimal increase, but I was told not to worry.

My whole pregnancy was entirely different to my previous two. I was incredibly hungry all the time, tired and grumpy. By 24 weeks I had a feeling that something had changed. Call it sixth sense. I was huge, and at first put it down to simply carrying twins, but I was also incredibly uncomfortable, my bump was tight and at 6 months looked 9 months. I had a scan at 26 weeks and my notes did say there was a slight increase in water. My usual consultant was away and I asked the consultant I saw, if I should worry. "No," they said. "It's fine".

The following week I went to Centreparcs for a much needed break with the family. By this point my bump was immense.

To be honest, I was sure something wasn't right. I was convinced I wouldn't make it through the week, but I did and having spent the week being stared at because I was so huge we went home. The next week I went for my 28 week



William

scan. Little did I know that our lives were about to change forever.

My scan showed that the water had significantly increased but because I was 28 weeks it was too late to treat the TTTS. It is very unusual to be diagnosed with TTTS so late in the pregnancy. Looking back I wonder if the TTTS had been there earlier but just not spotted. I will never know. My consultant arranged for me to see her again the following day and told me to bring my bag and be prepared to deliver the babies.

The next day after numerous scans and dopplers it was decided I should have an emergency c-section. By this point the twins were showing signs of problems and I was also having slight palpitations. Due to a lack of cots in my area, I was moved by ambulance to Liverpool Women's Hospital and my identical twin boys were delivered. I cannot say I gave birth to them, because I don't feel like I did - they were delivered.

William and Alex were both alive but poorly. William was the bigger twin, 1130grms, and had all the water to splash around in, Alex was much smaller, 840grms, and had more or less no water. He had been the stuck twin.

After recovery, I went and saw my little boys for the first time. It is a real shock to see your beautiful babies in incubators with tubes and ventilators, hooked up to monitors with numerous drugs being administered. The nurses try to warn you but it is such a shock.

William, the bigger boy, had received all the blood and as a result his heart was under a huge amount of strain, at the same time his blood resembled strawberry jam. It was incredibly thick. All a result of TTTS.

Over time his blood thinned and he came off the ventilator. He simply had to put on weight and grow.

Alex on the other hand was somewhat different. Because of his size he was so much more vulnerable. It was found that he had a hole in his oesophagus and that a feeding tube could not be inserted. He was nil by mouth for three weeks, he was ventilated for much longer than William. When he did get a feeding tube, he would not keep his food down. He did not put weight on and was generally much more poorly that his brother. Saying that, after a month in Liverpool they were both stable enough to be moved nearer home in Worcestershire.

William by this time was stable and improving day by day. I was able to cuddle him and breastfeed on a daily basis and watched him grow. Alex wasn't very well and was not handled as much; he still would not tolerate his feeds and had not yet begun breastfeeding. He was tiny and a poorly colour compared to his pink brother. When they were together on the two occasions that I could lay them together he was so tiny in comparison.

Then one day Alex was really good, he had a go at breast feeding and had tolerated his feeds, but then in the late afternoon he vomited all his food and stopped breathing. He was resuscitated and the following day was transferred to Bristol, a surgical hospital. After a week of fighting and an operation, Alex went to sleep in his daddy's arms and never woke up. He died of a massive infection as a result of necrotising entrocolitus, an infection in the intestine.

> "It is a real shock to see your beautiful babies in incubators with tubes and ventilators."

Back in Worcester, William went from strength to strength and on his original due date he was finally discharged. He has since had his first birthday and is making incredible progress.

Although the loss of Alex is unimaginable, we have William a much loved son and brother to my two eldest.

TTTS, although rare, I found out is surprisingly common. When I was in Liverpool I knew of two other mums who had also had TTTS, but you do feel very alone. I suggest to anyone who has TTTS or is at risk of it learns as much as they can about it. The signs are so subtle on the scans but if at any time you think something is wrong keep asking your consultant. I knew something was not right and had my consultant been at my last scan I may well have known I had TTTS then, not a fortnight later. Always trust what your body tells you, after all you know it best. If you are diagnosed with TTTS, ask as much as you can, and if you are early enough for treatment it is very possible that treatment is successful.

If you end up with a c-section and your babies are in a neonatal unit, life is a real roller coaster. Very often there are more bad than good days, but things do improve. There is lots of help and support available and never be afraid to ask questions. Most of all, spend as much time as you can with your babies, hold them as often as you are allowed and take loads of photos.

Although I lost one of my twins, and part of my story is very sad, William is our little success story, a trooper who survived TTTS and all the problems that result from it. If you are at risk of or have TTTS, it is not the end of the world. My story proves it.

FLEUR AND SASKIA'S STORY

BY SARAH AND IAN HILLS

Fleur (left) and Saskia (right) at 15 weeks

I moved to Zug in Switzerland in July 2009 to join my husband who had moved for work the previous September. I quickly became pregnant and had a scan at seven weeks and twelve weeks. Both scans only showed one baby. Although I was anaemic, the pregnancy was straightforward with no morning sickness or other complications. However, once I had reached twenty weeks I developed really bad backache and felt very sick. It was difficult to sit comfortably and I could not lie on my back. However, as this was my first pregnancy, I thought it was just back pain associated with being pregnant. I had another scan on 18 December when I was 22 weeks pregnant which revealed there were two babies! This was a massive, but very welcome surprise. The doctor confirmed they were identical girl twins and we named the first baby Fleur, and the second, Saskia. He measured both babies, and was concerned as the second one, was noticeably smaller. He immediately referred us to the hospital in Luzern which had more sophisticated equipment. He briefly explained that the babies could be transfusing and this could be an issue. We had a more detailed scan at Luzern, and it was confirmed that the babies had TTTS. We were then sent to the Inselspital in Bern as this was the only hospital in Switzerland which treats the condition. We arrived in the evening and met one of the doctors with specialist knowledge of TTTS who explained very clearly what the condition was and how it can affect both babies.

At this stage, Saskia (donor) had very little amniotic fluid and was unable to move in the womb. Fleur (recipient) had an amniotic pool of 6cm. The doctor outlined the options that were available which were doing nothing, draining the excess fluid or laser therapy. He explained the options and likely outcomes very clearly but gave us time to think about it. However, he did have a strong preference for laser therapy as this was the only therapy which would cure the condition. This had all happened very rapidly but we knew we needed to act quickly. We decided to go for laser therapy, although I did not yet meet the criteria as the pool needed to be 8cm. However, by 20 December, this condition was met, and the therapy was scheduled for 21 December.

> "Although I was anaemic, the pregnancy was straightforward with no morning sickness or other complications. However, once I had reached twenty weeks I developed really bad backache and felt very sick."

The operation however, was unsuccessful as when they entered the uterus a nick was made which led to some bleeding and made the fluid cloudy. The doctors were not willing to use the laser without clear visibility. However, as the therapy was performed in theatre, they were able to drain the excess fluid from Fleur's sac. I was upset and stressed after this as I knew that it was unlikely that the TTTS would stop and I was so worried about the survival of the babies. The drainage did alleviate all of the pain I was experiencing, however, by 29 December, the pain was back and a scan revealed that Fleur's pool was increasing again.

Laser therapy was scheduled again for 2 January. Although the babies were now deemed viable, in the event that they would need to be delivered their prognosis was not good. I found this very distressing to deal with, but remained convinced that laser therapy was the best option for both. The operation took three hours and 14 connections were severed. By my request and for my peace of mind, the midwives checked the babies' heartbeats every couple of hours. The therapy was successful and the transfusing stopped. Due to the specialism at Bern, the doctors were keen for me to stay in hospital until I reached 28 weeks. Unfortunately, as a consequence of the therapy, I developed thrombosis in my left thigh which was incredibly painful. A couple of weeks after the operation I also had a suspected small embolism leading to a tachycardiac event, which also was not pleasant!

As I was in hospital I had daily CTGs and scans at least twice a week. Although

the babies were continuing to develop and grow, there was concern that Saskia was experiencing placental insufficiency as she was still considerably smaller than Fleur, although the pregnancy remained stable. However, at 29 weeks (and on the day I was due to go home!), a CTG showed a transfusion from Fleur to Saskia

> “The girls are continuing to do amazingly and are very healthy and content babies and have exceeded everyone’s expectations after such a difficult pregnancy.”

which we were told was exceptional and not known to have happened before. Due to Fleur’s heart rate being in excess of 190 beats per minute, they begin preparing for an emergency caesarian. However, the situation stabilised and both Fleur and Saskia’s heart rate returned to normal. The doctors thought this reverse transfusion was a one off. However, I had to remain in hospital as the pregnancy was deemed high risk.

After this point, both the babies and me remained in a stable position and I was discharged at 32 weeks by mutual agreement. A caesarian was scheduled for 34 weeks due to the riskiness of the pregnancy. This date was in line with the policy of the hospital and with agreement from my husband and me. I had weekly CTGs although the one at 31 weeks showed Saskia’s heart rate had severely dropped so I was rushed to hospital with the anticipation of an emergency caesarian. Again, the situation stabled and I was discharged after being monitored for five days.

I finally made the agreed caesarian date of 15 March and Fleur (at 2330g) and Saskia (at 1915g) were delivered at 8.10am with very audible cries! Both babies were incredibly healthy and required no support. Saskia was put on a glucose drip as per hospital protocol as she was below two kilos. However, neither baby required any interventions, and although they were monitored by the neonatal unit, they joined me after three days. The three of us were discharged a week after the delivery date once I had recovered from the operation.

The girls are continuing to do amazingly and are very healthy and content babies and have exceeded everyone’s expectations after such a difficult pregnancy. We were expecting that the babies would have a number of complications and we were envisaging a long stay in hospital however, this was definitely not the case. There is still a weight discrepancy of 600g between Fleur and Saskia but both are within the 25 percentile. We just feel so lucky to be in this position and are enjoying every minute with Fleur and Saskia.

AVIA AND ELIA’S STORY

BY ASNAT DOZA

Avia and Elia, pictured with their brothers. Raphael, Gabriel and Guy (3 out of 4 big brothers) Girls: Avia (on the left) and Elia (On the right). Avia and Elia are 10 months old in this photo.

Before I start to tell our TTTS story, I want to say that both our daughters survived and are progressing extremely well. They are a year old and they have already brought us great joy and happiness. We smile at them with amazement every morning, and they are the last thing we look at before we go to sleep. They are our very own miracle, and I doubt we will ever see anything more amazing!

TTTS was showing in our case on the first baby scan at week 11, and was originally mistaken as Down’s syndrome. A second scan by a senior consultant a few days later confirmed TTTS. Our centre was very much aware of the syndrome and immediately booked us a series of weekly scans. We were offered to terminate the pregnancy since the chances of positive pregnancy outcome were lower than average. But the consultant suggested that no-one can tell how this pregnancy will develop. The situation stayed stable for a further seven weeks. Every scan showed slight changes in the TTTS, but it was still only monitored and no action was required.

Early in week 18, we were told that the water pools had changed dramatically and the level of TTTS was changed to level 2. We were very upset. Further tests that afternoon revealed that the deterioration suggested level 3 TTTS and that an intervention was

> “The weekend between the scan and the laser ablation was the worst weekend of our lives.”

Avia and Elia, aged 2 months, with their mother at the end of their hospital stay

now imminent. Our centre could no longer support our case and so we were referred to Queen Charlotte's Hospital in London for a laser ablation.

The weekend between the scan and the laser ablation was the worst weekend of our lives. Our household which is normally a happy noisy place became very quiet. Anxiety was in the air. We all had many things to organise - babysitters for the children we would leave behind, food and instructions to friends who were left in charge, on top of packing for a hospital stay. But hovering above all that was a heavy feeling that we might not make it this time. We might not save these babies. Our only ever twin girls.

When we arrived at Queen Charlotte's on Monday morning the TTTS deteriorated further and a set of consultants were trying to decide whether they could save the twins. Again we were offered to terminate the donor baby, terminate the pregnancy or have a laser ablation in an attempt to save both girls. We went for the third choice.

While the team were preparing the theatre, we were sent to have lunch in a nearby shopping centre. Both my husband and I had no appetite, but we had something to eat anyway. The operation took 32 minutes. We saw everything on the screen and the whole process seemed like it was out of a science fiction movie. 45 minutes later we were told both babies survived the operation and that the TTTS seemed to be improving. It was delightful news. The following morning the donor baby was seen moving during the scan. She was 'unstuck' and in a pool of water. While we were delighted, it was clear we are not out of the woods yet. Many things could still go wrong.

Queen Charlotte's released us a week later, and we were followed by our local centre for the rest of the pregnancy. There was a high risk of miscarriage in the following six weeks, so I decided on bed rest. Even though some consultants suggested it would make no difference, I felt I had to try and do something. TTTS seemed to have been resolved, but the donor baby had a lot of catching up to do.

On week 26 I was hospitalised with bleeding and water leakage. It was a nightmare. Somehow we all kept positive, but looking back at ourselves I can't quite understand how we managed.

The babies chose to arrive at week 28 + 7 hours. It was an emergency caesarean. Avia the ex-recipient was born 2 pounds 14 ounces and Elia the Ex-donor was only 1 pound 14 ounce. A dear friend described it as: "less than a bag of sugar". Look at them now!

CHARLOTTE AND GABRIELLE'S STORY

BY HEATHER AND PAUL MABER

I was five weeks pregnant when I found out I was pregnant, then after a bleed, a scan at 8 weeks showed that I was still pregnant – with twins! We were immediately warned by the Antenatal Clinic staff that there were a lot of risks associated with twin pregnancies; don't go home and start reading up about all the risks yet, just get to 12 weeks first. The next step was to determine the choronicity of the pregnancy, something that would prove an extremely important factor in my pregnancy.

Twin pregnancies render the 16 week blood test useless so we booked ourselves in to have an NT scan at a local private clinic. All was fine with the results, and while we were there the consultant asked us if we knew the choronicity yet. As we didn't, he checked and concluded

(l-r) Gabrielle & Charlotte at 8 weeks old.

(l-r) Gabrielle, Heather & Charlotte at home - 5 months old.

there was only one placenta, two sacks, therefore I was pregnant with identical twins. We were very excited by this news, but also wary – we knew that identical twin pregnancies carried higher risks of miscarriage.

The next day we returned to our local NHS hospital for our 12 week scan (to determine the choronicity); even though we had had it confirmed the previous day we went along anyway. The sonographer had a look and announced there were two placentas; I was definitely carrying non-identical twins! Oh dear. At this point I mentioned the scan the previous day and what the consultant there had concluded. Not at all happy with this, the sonographer announced "I can assure you that I do far more scans than he does!" She did however, when pressed, admit that she wasn't 100% sure.

After the scan I spoke to one of the on-duty midwives and requested that I be scanned as if expecting identical twins until it could be conclusively determined otherwise (by now I had done a lot of reading on twin pregnancies and knew that frequent scans were very important). The midwife booked me in for my 20 week scan but worryingly had no idea if I should have any further scans over the next eight weeks. She booked me in to see my consultant the following week due to the discrepancy in choronicity diagnosis. Luckily my consultant decided I needed to be scanned by the head radiography consultant – whatever his conclusion we would go with that. What I didn't realise was that choronicity needs to be detected as early in the pregnancy as possible – by 14 weeks it gets very difficult to detect the number of placentas. At this point I was three days away from 14 weeks.

The radiography consultant was fantastic; he took his time over the scan and eventually agreed with the first diagnosis: we were definitely having identical twins. He then ran through the risks associated with this form of pregnancy (something no-one else had bothered to do) including Twin to Twin Transfusion Syndrome (something I had already briefly read up about). We knew we needed frequent scans in case TTTS were to develop but so far opinion on when these scans should commence differed wildly. Luckily for us, he decided I needed fortnightly scans – these were booked in for me immediately.

Over the next couple of months my pregnancy progressed well, and at 15 weeks we found out we were expecting girls.

> "I was pregnant with identical twins. We were very excited by this news, but also wary – we knew that identical twin pregnancies carried higher risks."

However, after my 22 week scan our consultant called us in: it looked like I had started to develop TTTS. We were stunned. But this did explain my suddenly large belly and how uncomfortable I become (although when I had mentioned this at a previous appointment my consultant's reply had been "Welcome to the joys of a twin pregnancy"). There was nothing further our local hospital could do (nor any hospital in Wales) for us so we were immediately referred to a foetal medicine consultant at St Michael's Hospital, Bristol. Luckily he could see us the following morning. Our hospital didn't give us any information on the condition so we headed home and started trawling the internet; things didn't look good, there seemed to be more negative stories than positive – we also realised how newly 'discovered' this condition was, and also how new the treatments were (and how few options we actually had).

(L-r) Gabrielle and Charlotte, 6 months old.

Once at St. Michael's we were introduced to the consultant and immediately taken to a consultation room and scanned. After the scan, he delivered the news we had been dreading. Yes, it was TTTS, and it was advanced – on a scale of 1-5 we were already at stage 3B. He was blunt, but that was what we needed; we didn't want a false bedside manner right now, we needed the facts – however hard they were to hear – so that we could decide what to do next.

The recipient twin was very poorly; she had far too much amniotic fluid in her sack which had put her heart under a lot of stress, it didn't look good for her. The frightening thing was that this condition had gotten this serious in just 14 days – thank God we were being scanned every other week.

We listened calmly while the consultant gave us our options. Option one we could do nothing at all, but given the amount of excess amniotic fluid it was pretty much guaranteed that I would go into labour over the next 48 hours. Option two: terminate the pregnancy. Option three was to opt for the pioneering, and still relatively new, laser surgery on the placenta. At this stage, draining the excess fluid was not an option for me. We asked what the odds were of the surgery being a success, and again he was very honest with us: there was a 40% chance that both babies would die; there was a 40% chance that

one baby would die, and there was only a 20% chance that both babies would survive. And on top of this we wouldn't know how the TTTS had affected either baby (should they survive) until after they were born. We had 30 minutes to decide. We were devastated, but what choice did we have – we opted for the surgery.

Within two hours I was in surgery (wide awake), Paul was with me. 45 minutes later it was all over. Now we had to wait. I was in quite a bit of discomfort initially, but that soon wore off. After a few minutes the consultant came in to see how we were (all) doing. First bit of good news: both babies had survived the surgery (something he admitted he hadn't expected); second bit of good news: the surgery had gone a lot better than anticipated, all offending blood cells had been cauterised and an entire litre of fluid had been drained from the sack surrounding the recipient twin (I already felt a lot more comfortable). But now we had to wait…

The procedure didn't require an overnight stay, but I did need to be observed for another couple of hours – the initial concern was that as a result of the procedure I might go into labour. This luckily didn't happen, and we were allowed home with an appointment to return four days after the operation.

After the longest weekend ever we returned to Bristol. Nervous and anxious we were shown into the consultation room once more. He started the scan by looking for both heart beats to put us out of our misery – they were both there! We could now relax slightly while all the other painstaking measurements were recorded. More good news: both babies were alive, the fluid in both sacks was returning to normal levels and the recipient twin's heart even showed small signs of repair. The consultant was extremely pleased with progress so far; he admitted that pre-surgery last Friday he never imagined that this would be where we were now. After a further scan at Bristol one week later we were discharged and transferred back to our local hospital.

Heather & Charlotte, Charlotte is 8 weeks old here

My pregnancy progressed well over the next month, but at week 29 a scan showed that the TTTS was returning. Both babies were still healthy so it was decided that the best thing for everyone now was to deliver them. Luckily two weeks prior I had been given the steroid injections to aid the development of the babies' lungs should an early delivery be necessary. We had also spoken to a paediatrician who had explained to us what would happen if the babies arrived early, and we were given a tour of the Neonatal Unit. We would recommend to anyone expecting multiples that they request a tour of their local Neonatal Unit – if you don't end up there, great, but if you do at least you will be slightly more prepared.

By 2pm on Thursday 28th January 2010 I was in a hospital gown ready for my C-Section. Charlotte arrived at 2.51pm, Gabrielle three minutes later. Gabrielle was stuck, but luckily there were two consultants performing this C-section (curious to see the outcome of a TTTS pregnancy, I suspect) – and another 14 members of staff! With me and Paul it was pretty crowed in this theatre. Paul was able to see both girls before they were whisked away to the Neonatal Intensive Care Unit (NICU) ward. Meanwhile I am still lying on the operating table, unbeknownst to me, bleeding heavily – my placenta had crumbled when they tried to remove it so they were frantically trying to stop the bleeding. Later one of the consultants told me she had seen this before and that it was possibly as a result of the laser surgery.

Both girls were alive but weighed a lot less than the scans had estimated: Charlotte (the donor twin) was 2lb 1oz; Gabrielle was 2lb 2oz and a half. They were pretty poorly, but stable; they were showing themselves to be real little fighters.

The staff in NICU was amazing – they were very supportive and kept us positive and focused. Over the coming weeks and months we experienced a lot of ups and downs, and many setbacks, but suddenly the girls started to get stronger; their oxygen requirements were reduced to nothing and they were taken off all monitoring.

> "The staff in NICU was amazing –they were very supportive and kept us positive and focused."

After 10 weeks on the neonatal ward our girls were finally ready to come home. It had been a relentless emotional rollercoaster ride for us all but suddenly their consultant was telling us to prepare for their discharge! Excited and a little nervous we finally said our Thank Yous and Goodbyes to the Neonatal staff, doctors and consultants on Thursday 8th April 2010, 10 weeks after the girls' birth, and exactly one week before their estimated due date. The girls now weighed just over 4lbs each.

Four months after arriving home the girls are doing really well; they have settled into home life with their big brother Luke (who adores them), are gaining weight rapidly and have just started cutting their first teeth. Life is pretty hectic but lots of fun.

JACK AND OLIVER'S STORY

BY BECKY GREEN

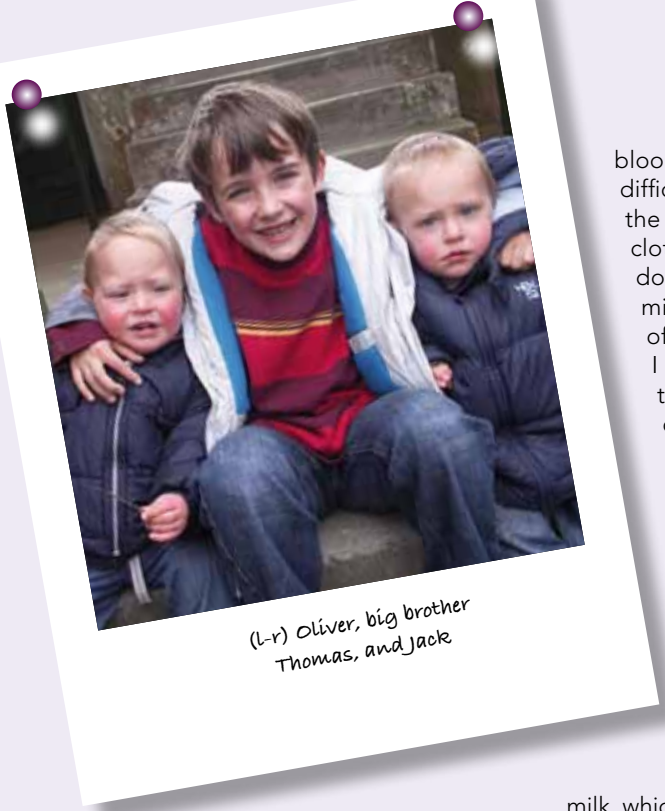
We have three children - a 7 year old boy, and twin boys who are just 2.

I have Polycystic Ovary Syndrome (PCOS), and was under consultant care due to loss of a previous baby, so had a scan at 11 weeks, which was when we all found out that I was carrying twins. I was referred to Kings College Hospital and had a scan at 13 weeks, and I had another one at 16 weeks when the twins were diagnosed as Monochorionic Diamniotic (MCDA).

I was given one more scan at my local hospital in South London at 18 weeks before the family all moved to Salisbury. Once in Salisbury I had regular scans (increasing to once every two weeks), which picked up a difference in the babies' growth at about 30 weeks. I was given steroids 'incase' but things evened out and the babies continued to do well. At 38 weeks another routine scan saw that there was once again a difference in growth (this time the other way around) and I was booked in to be induced the next day.

The boys were born naturally (gas and air) the next day, and weighed 5lb 1oz and 5lb 2oz. Jack was very pale and quiet, whereas Oliver was very red and loud. There was one consultant who helped at the end of the birth as I was quite tired, one midwife and one midwifery student. The midwife commented to my husband that the placenta was very think and healthy on one side and very thin and pale on the other, but this information was not passed on and it was 'thrown away'. The boys both came back to the ward with me, and we had three days of them not wanting to feed much, and the doctors having great difficulty getting blood samples. Several doctors and consultants saw me with my '2 tone' babies during this time, and commented on the difference in colour, but when they asked about the weights of the boys they said no more. On the third day the midwives were obviously getting concerned about the difficulties in feeding (although they were subtle about this and didn't alarm us). They bathed the babies and tried to get them latched on, but there was nothing really

Jack and Oliver in the hospital (Oliver on the left - recipient)



(L-r) Oliver, big brother Thomas, and Jack

happening. When the doctor once again failed to get a blood sample from Oliver (his blood clotted whilst coming out as it was so thick), another consultant was called, who immediately realised that the boys were suffering from TTTS and rushed us all to SCBU.

Jack was given a blood transfusion to help his anaemia. Oliver needed more care - he had blood taken from his belly button and water put in, he was placed in an incubation and had light therapy to help the high levels of jaundice that were being caused by his body breaking down some of the excess red blood cells.

Jack rallied well and was allowed back to the ward with me the next day, but Oliver needed a day in the incubator, and then slowly reducing levels of light therapy which meant he stayed down the corridor in SCBU for the next 10 days. He also had several blood tests each day as it was still difficult to get blood samples to the lab to be tested before they clotted! Being around whilst the doctors tried for sometimes 30 minutes to get a sample was one of the hardest things to see, but I chose to stay with him and tried to comfort him as best I could. Due to the difficulties in getting the samples tested it was quite difficult to get accurate information as to how Oliver was doing, especially if I happened to be on the post natal ward when the SCBU doctors were doing their rounds!

During this time the staff encouraged my wish to breastfeed, and provided me with pumps to express milk, which Oliver was given through an NG tube until he was stronger, and which both boys were given top-ups of until it was seen that they were taking enough milk to be putting on weight by themselves.

After 10 days we were able to take both the boys home. Oliver still had his NG tube, but I was trained to use it, and this only stayed in for a few days. The boys were never big feeders, needing 3 hourly feeds for several months, and always at the bottom of the chart, but they grew steadily. I was able to fully breastfeed them for 6 months, and then partially breastfeed them until 11 months.

Both boys are now fine, and further checkups on their development have shown them to be doing well. Oliver was a little slower at standing and walking than Jack (5 months to be precise!) but this was due to him having loose ligaments, and things have averaged out now.

FREDDIE AND BEN'S STORY

BY EMMA RICHARDS

Having had a very straightforward first pregnancy with my son Henry, I was a little concerned about some light spotting I was having early on in my second pregnancy. This was the reason I ended up going to our local hospital to have an early scan at 8 weeks to check all was ok. I received two lots of good news from that scan; the first being that everything looked fine and the second being that I was expecting not one but two babies - twins! Admittedly the second lot of good news took a bit longer to sink in than the first!

In light of this bombshell, my husband, Nick, and I assumed we would have a couple more appointments and scans than we did for my first single pregnancy, so we were fairly surprised to learn that our next scan and appointment at the hospital would be at 20 weeks. Normally a dating scan is carried out at 12-14 weeks but because I had effectively had this scan at 8 weeks it was no longer needed. I was really disappointed and a bit uneasy about having such a long gap before having another scan, so Nick and I decided to pay for a private nuchal fold screening scan at the Leeds Screening Centre (as it turns out the best money we've ever spent!).

The nuchal fold screening scan was carried out at 12+4 weeks and this is when we first found out there was a problem. At this stage the worry was that both the babies (because they had also just been confirmed as identical) would have Down's syndrome – their risk factor was calculated as a 1 in 4 chance. Having discussed what happens next and in a bit of a blur we were on our way to Leeds General Infirmary (LGI) with an appointment to see a Foetal Medicine Consultant, who specialises in twin pregnancies. She immediately carried out a CVS test and advised us that we would be having an appointment with her every fortnight to keep an eye on our twin pregnancy. The CVS test ruled out any chromosomal defect. However, at our following appointment, she explained that the nuchal fold result could be a possible indication of other problems, one of which was Twin to Twin Transfusion Syndrome (TTTS). I think like most people who experience it, we had never heard of TTTS before and found all the information we were being given about what it is and survival statistics extremely distressing and difficult to take in. Having said that, I was in complete agreement with our Consultant that I would rather be aware of the potential risks to my pregnancy and be monitored for them, than not.

> "One of the many horrid aspects to TTTS is that the chances of something happening to one or both your babies never really goes away."

On our third visit to LGI at 16+4 weeks, our babies were diagnosed as suffering from TTTS and an appointment was made for us to see a Consultant in Foetal Medicine at RVI in Newcastle, the following day. It was explained to us that the only course of action to tackle TTTS was to have laser surgery and at that time Newcastle was our nearest. Added to this, the laser surgery could only be performed from 16 weeks at the earliest because before this it would be too traumatic for the babies to survive. Knowing that we had only recently reached the 16 week mark made me think the worst. In fact I went out to a pre-planned supper with some close girlfriends that night (anything to take my mind off what was about to happen) and at the back of mind all I was thinking was "This is it, I'm going to lose my babies tomorrow".

As it turned out, when we arrived at Newcastle we were told although our babies were indeed suffering from TTTS it wasn't as far along as first thought. It was confirmed that we would definitely need the surgery but we had a bit more all important time for the babies to grow and therefore hopefully get a bit stronger. We were asked to come back to Newcastle the following week (a bit of a schlep from Harrogate but not something we even thought about at the time!). The following week I was scanned again and although the TTTS was progressing it was progressing slowly, therefore our Consultant felt we could just about go another week to give the babies even more time to get stronger as it was still very early days in terms of laser treatment.

The following week at 18+4 weeks pregnant I underwent the laser surgery at Newcastle RVI. I was so scared and not just about what was going to happen to the babies but also about having this procedure done to me. It ended up being a most surreal experience. The anaesthetic administered was described by the anaesthetist as like have a few large gin and tonics – you are aware of what is going around you but you don't really care! So true! I was so relaxed I almost fell asleep. Unfortunately Nick was stone cold sober and therefore aware of everything going on around him including when our Consultant thought, after 20 minutes of trying to perform the surgery, he would have to call it off because of the position of the placenta. If that had been the case then there would have been nothing else that could have been done – unthinkable. Thankfully, after pumping more water in to stretch my tummy, he had one more attempt which was successful. Without going into too much detail, the laser surgery is to separate and cauterize any fused blood vessels in the placenta which are causing the shared blood flow between the babies. In my case he had to zap all the blood vessels about a third of the way along the placenta because he could not get the right angle, due to the way the placenta was laying, to see which ones were fused and where.

After the surgery, our Consultant came and had a chat with us to say that, although he was happy he was able to carry out the procedure in the end, it was far from ideal the way in which he had been able to perform. In effect if our babies survived the trauma of the procedure plus beat the survival odds for TTTS, one of them was developing from only two thirds of a placenta and the other one from only a third. The outlook, we were told, was not great.

The scan half an hour after the laser surgery showed that they had got past the first hurdle and had survived the

OUR STORY
BY KAREN LINTERN

I was 32, my partner 39 and we were delighted to discover we were pregnant with our third child. We already had a 10 and 8 year old. I had my first scan at 14 weeks 4 days. We were even more delighted when it turned out that we were pregnant with our 3rd and 4th child - two heads had appeared on the monitor. It was thought that the twins were monochorionic. monoamniotic (MCMA) at this scan.

At 20 weeks I was looking nearly full term singleton pregnancy – medical staff had commented how big I was and I had asked if it was normal but I was told it was like this due to being twins. I didn't know how I would make it to Christmas, let alone March when they were due. I was breathless without exertion and my stomach grew so fast that it was itchy and shiny. The month prior to my 2nd scan, I saw the midwife, GP and Registrar.

I had my 2nd scan at 21 weeks and 1 day. The sonographer stopped scanning to check with a colleague and said that there was a difference in size. She sent us to a consultant in the same building. On our way up, we read in the notes that severe Twin to Twin Transfusion was suspected. The Consultant was not

Chloe, the larger recipient twin (left) and Abbie, the donor twin (right)

> "I was breathless with exertion and my stomach grew so fast that it was itchy and shiny."

procedure. We were then sent home with follow up appointments every week back at LGI to monitor the babies.

These appointments soon took on a routine. The night before and the morning of the appointment we would be feeling extremely apprehensive about what we may be told at the scan. Our consultant was fantastic – she started scanning straight away and the first thing she did was confirm she could see two heartbeats. After that, Nick and I could take a deep breath and then she would start taking all the various measurements to check their growth, fluid levels around them etc.

One of the many horrid aspects to TTTS is that the chances of something happening to one or both your babies never really goes away. The outlook may be improved as a result of the surgery, although that brings its own survival statistics, and as the weeks progress you can allow yourself to get a bit more confident as they start to reach viability milestones, however we were warned by our consultant right up until about week 30 not to really start planning anything or buying anything in preparation. You don't have to be the smartest cookie to understand what that really means and therefore you end up living in limbo – you can't help but start bonding with the babies growing inside you but you can't enjoy it and force yourself to try to stay detached (impossible) in case it is all suddenly taken away.

After various additional scans, including a detailed heart scan and brain MRI, we reached our big milestone – 34 weeks. We had been told that if I could 'hold on to' the babies until week 34 then they would have a better chance of survival on the inside up to this point and then apparently a better chance of survival on the outside after this point. Therefore a planned caesarean was booked for 34+2 weeks. We were warned that the babies could require anything from minimal support, i.e. in terms of feeding and gaining weight, all the way through to having to be transferred out of our local hospital for full intensive care support, i.e. can't breathe for themselves. Through our consultant, we were invited to have a look round the special care baby unit (SCBU) at the hospital and talk about any concerns we may have had with the doctors.

On the 28th August 2007 I gave birth to two amazing little boys who announced their arrival at full volume! So great to hear, given it meant they were breathing just fine on their own. Their weights were 5lb 5oz and 5lb 2oz, which was fantastic as TTTS normally means one twin is significantly smaller than the other. They spent a couple of weeks in SCBU putting on weight, being treated for a slight touch of jaundice, which is very common with premature babies, and learning to feed rather than be tube fed, before being allowed home.

Nick and I would both say that the pregnancy was the worst time of our lives – thank goodness we had Henry who did an awful lot to take our minds off it in between appointments. However, as soon as they were born, it immediately felt like those awful months hadn't existed, probably because we were straight into looking after newborn twins and a just-turned two year old. Every so often it pops into our heads or something will remind us of it and I can't tell you how lucky we feel that we had such a happy ending to our experience.

Today we have 3 gorgeous boys – Henry, 5 and Freddie and Ben, who will be 3 at the end of August. Life is completely chaotic, noisy, fun and everything you'd expect it to be with 3 young boys.

available, the midwife had the situation in hand and we were sent home.

The following Monday we were seen by the clinicians, who were surprised the TTTS hadn't been discovered beforehand. The pregnancy was monochorionic diamniotic (MCDA). The little donor twin was stuck right up under my ribcage and her bladder could not be seen. The larger recipient twin had a thickened heart. It was severe TTTS; there was a discrepancy of 54% in the estimated fetal weight and the deepest pool of amniotic fluid was 14cm.

The options for us were to let nature take its course or go ahead with laser treatment. We opted for laser treatment.

I was operated on the following day. They made a small incision into my stomach and entered the womb with a laser and camera. We could see the operation being carried out on the monitor at the end of the bed. I had a local anaesthetic - it wasn't painful. The placenta was lasered roughly down the middle and 2.7 litres of fluid drained. The recipient twin was seen very clearly on the monitor after the operation.

The babies were checked an hour after and they were ok, so home we went. I was really tired after the operation for a couple of days and took bed rest and ate healthily.

We returned to Kings College Hospital a week later to see whether the babies had survived – luckily they did. The fluid around the little baby had increased and the larger baby's fluid had decreased. Also the recipient baby's heart problem had resolved and the donor's bladder could be seen.

(L-r) Chloe and Abbie

After that, we just took one week at a time, thinking the longer they could remain inside, the bigger they would grow and the better chance they would have. We were warned we might have a premature labour and knowing that the donor twin was that much smaller than a baby of this gestation, thought they stood less chance than other babies born early. After the operation at 22 weeks 5 days, the estimated weights were 1lb 2 oz's and 9oz's so it was a celebration when twin 2 reached 1lb. We bought a doppler to listen to them daily to check they were ok.

It was decided that the best time for delivery would be 34 weeks. A Caesarean was performed 34 weeks and 5 days and our two beautiful baby girls were born. Although they were identical, in size they were not – weighing 3lb 1oz and 3lb 13oz.

They were taken to the high dependency unit – linked up to all the monitoring leads and feeding tubes. The next morning they moved into special care, where they spent approximately three weeks – in incubators, then a hot cot, then a normal cot. They also spent time under the UV lamp and had head scans.

After being discharged, they continue to see the consultant to monitor their progress. We have had concerns following our donor's head scan about the size and shape of her head, but as they both seem to be happy progressing babies and that us parents have larger than average head size, they haven't had to have further tests. Our donor is still being seen by the hearing screening department, but again nothing significant has been found. The recipient twin has been ahead with just about everything, our donor having a heavy head/stiff neck and she found it hard to lift her head up to crawl. We saw a physiotherapist and with time this has corrected itself enough to stop attending. At 16 months the recipient is walking and the donor is just starting to. The recipient remains heavier and taller and we were told that the donor may catch up in 1-2 years, in their teens or never.

Without the work of the Harris Birthright Trust at Kings College Hospital we would not have our precious treasures in our lives and through all the scares we came out lucky.

Our main concerns remain; that given this syndrome usually occurs between the 1st and 2nd scan can go undetected unnecessarily and with tragic outcomes. At the first scan when twins are discovered, additional scans should be booked to look out for this. Parents should be given information about what to look for. Midwives should be trained to deal with multiple pregnancies. We felt let down in the initial period of the pregnancy as in hindsight it was obvious what we had - the symptoms were staring at us and the people caring for us in the face. We are so thankful that the sonographer detected it and we felt really well cared for at Kings.

“They made a small incision onto my stomach and entered the womb with a laser and camera. We could see the operation being carried out on the monitor at the end of the bed.”

GRACE AND OLIVIA'S STORY

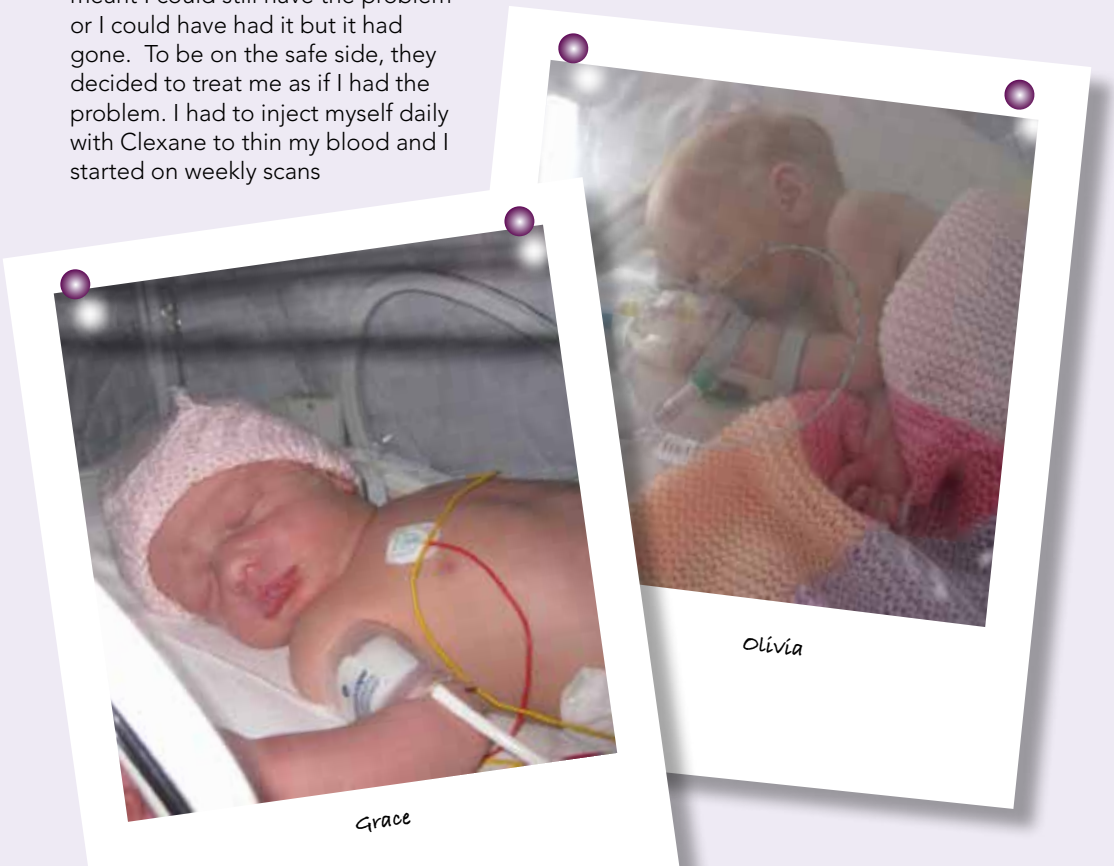
BY DEBBIE WHIPPS

This is our story so far.

After Rich and I got married we decided to try for a baby. I came off the pill and thought everything would just happen as normal. Unfortunately for us we had a number of miscarriages, the last of which was in February 2009. I was being seen by a specialist at this point, trying to get to the bottom of what was causing the miscarriages when I fell pregnant again.

At the same time, one of my test results came back as a 'weak positive' result to sticky blood. The weak result meant I could still have the problem or I could have had it but it had gone. To be on the safe side, they decided to treat me as if I had the problem. I had to inject myself daily with Clexane to thin my blood and I started on weekly scans with my specialist.

At the first scan, when I was about 6 weeks pregnant, they could not pick up a heartbeat so I was sent home and told to come back the following week. That was such a long week for us. When we returned, a heartbeat was spotted and Rich and I were over the moon. Because of our previous problems, the consultant continued to scan us weekly until 11 weeks when he handed me over to the care of my midwife. At no point during these scans did he mention that we were carrying twins, so you can imagine our surprise when at our 12 week scan the sonographer casually said (assuming we knew from our previous scans) that we were carrying twins!



After all our problems, we were overjoyed, shocked and completely amazed that we were having identical twins.

The sonographer called in her manager who briefly explained the differences between the types of twins and explained that because we were carrying monochorionic twins, one placenta, two sacs, they were identical and there could be more risks associated with the pregnancy. He briefly explained about TTTS and said that we would be scanned every two weeks and would see the consultant at every scan too.

So our journey started. Each scan seemed to show things were going well, the babies were growing well, I was growing well and, other than the normal pregnancy issues, all seemed fine. At about 26 weeks twin one started to grow more than twin two. She was getting bigger at each scan and there was more of a gap between the two. We kept asking our consultant if this was a problem, but he kept saying that it was fine and nothing to worry about.

Towards the end, I was starting to get really big, was struggling to walk and the pressure down below was starting to get very uncomfortable. At my next routine midwife appointment, it was found that my blood pressure had shot up and I was taken into hospital with suspected pre-eclampsia. I was now 36 weeks.

Other than the blood pressure, they still seemed happy with the babies and decided to wait for my C-Section which was booked for 37 weeks, but they wanted me to remain in hospital at this point to monitor my pre-eclampsia. My consultant had more or less insisted on a C-Section, due to there being more risks associated with identical twins.

The morning of my C-Section arrived and we were both very excited that we would be meeting our girls very shortly. The C-Section went well; Grace was born first, weighing 6lb 15oz and was handed to me for a cuddle. We noticed that she was extremely chubby and very red and bloated, but didn't really think anything of it until Olivia was born a minute later, weighing 4lb 9oz.

I could see her, to my side, being handled by the doctors. She was extremely small compared to her sister and very white, like a little ghost and it took a few minutes before she made any noise. At this point they realised something was wrong and came across to take Grace, saying they just needed the paediatrician to check them over.

Still not realising really that anything was too wrong; I was stitched up and taken into recovery, where our two girls were in their incubators being checked over by a paediatrician. It was at this point that we were told that they had TTTS and needed to be taken to NICU. We were shocked, as throughout my pregnancy we were told nothing was wrong and the girls were healthy.

I was so upset. I had to spend the day in recovery as I was feeling quite sick and could not see my girls. Other ladies were coming back into recovery with their babies and we didn't have ours. Rich kept going up to NICU to see the girls and relay to me what was happening.

It wasn't until later that evening, many hours after the girls had been born that I got to meet them properly. The following day a consultant explained what was happening with the girls. Grace (the recipient twin) had to have blood taken out of her and her blood thinned, while Olivia had to have blood put in her, along

> “After all our problems, we were overjoyed, shocked and completely amazed that we were having identical twins.”

with various other treatments that they both needed. It was really hard to take it all in and to remember what was said to us. They were both hooked up to so many wires and each had feeding tubes inserted to help them feed.

The girls spent a week in NICU and then eventually joined me on the Transitional care ward where we remained until they were sure they had both established a good feeding routine. We were then finally allowed home. The first few months were extremely difficult as both the girls were really hard to feed, and it took Olivia quite a while before she started putting on much weight.

Now though they are both nearly 10 months and are doing really well, both weigh more than the average baby at this age! And Olivia has definitely caught her sister up.

I later found out, when I went to my GP to be signed back on for driving from my C-Section that my placenta had been sent away for analysis. No-one told me this would happen! The analysis showed that half of the placenta was really healthy but the other half wasn't. I have so many questions about why this wasn't picked up during my pregnancy, but no-one has ever given me the opportunity to ask these questions.

I feel that we were not given enough information about TTTS during my pregnancy and although the nursing staff were fantastic during our stay in hospital I still feel that we were not properly informed about TTTS after the girls were born.

I think if I had been given more information during my pregnancy about the signs of TTTS I would have pushed more with my consultant when the girls started to show a difference in weight. I would advise anyone in a similar situation to ask as many questions as possible, to learn about the condition and to push for answers if you feel something isn't right!

(L-r) Grace and Olivia

WHERE TO GET FURTHER SUPPORT

THE TWINS AND MULTIPLE BIRTHS ASSOCIATION (TAMBA)
2 The Willows, Gardner Road, Guildford, Surrey, GU1 4PG
Admin: 01483 304442
Twinline: 0800 138 0509
www.tamba.org.uk
Facebook: http://www.facebook.com/pages/Twin-to-Twin-Transfusion-Syndrome-Support-Group/154700304559449?created#!/pages/Twin-to-Twin-Transfusion-Syndrome-Support-Group/154700304559449?v=wall

MULTIPLE BIRTHS FOUNDATION
Hammersmith House, Level 4, Queen Charlotte's and Chelsea Hospital, Ducane Road, Hammersmith, London, W12 0HS
Telephone: 020 3313 3519
www.multiplebirths.org.uk

BLISS (for babies born too soon, too small, too sick)
9 Holyrood Street, London, SE1 2EL.
Family Support Helpline (freephone): 0500 618 140
www.bliss.org.uk

STILLBIRTH AND NEONATAL DEATH SOCIETY (SANDS)
28 Portland Place, London, W1N 4DE
Telephone: 020 7436 5881 (9.30am – 5.30pm Monday to Friday; and 6pm-10pm Tuesday and Thurdsday)
www.uk-sands.org

The Twins and Multiple Births Association (Tamba) is a charity set up by parents of twins, triplets and higher multiples and interested professionals in 1978. It is the only UK wide organisation that directly helps parents and professionals to meet the unique challenges that multiple birth families face.
It undertakes research, campaigns and provides information and support to over 10,000 members and supporters each year. Our work is funded through membership fees, fundraising activities and the delivery of our services. You can download our latest Annual Report and Accounts for 2009-10 now (pdf doc).

Charity Number 1076478, Scottish Charity Number SC041055, Registered Company Number 3688825
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