

News release

Friday December 3

Embargoed until Tuesday December 7

Twin mum shocked by TTTS diagnosis feared uncertain future for her babies

Tuesday (December 7) marks World Twin to Twin Transfusion Syndrome Awareness Day.

TTTS (Twin to twin transfusion syndrome) is a rare but life-threatening condition that affects 10 to 15% of identical twins that share a placenta (monochorionic twins). TTTS can also occur in triplet or higher order pregnancies with monochorionic twins.

TTTS can have serious consequences for the babies and mothers are monitored very closely by their doctors.

First-time mum Abbie Hofbauer was stunned when at 17 weeks into her twin pregnancy she was told her girls faced an uncertain future because of the devastating condition twin-to-twin transfusion syndrome (TTTS).

"I had two shocks in a matter of weeks," said Abbie from Northampton.

"First was that I was expecting identical twins, then the fact that I could lose them because of TTTS.

"It was not a planned pregnancy as I had just started my dream job, and I was very sick early on so it was thought I might be having an ectopic pregnancy.

"At 13 weeks, during a private scan I was told I was expecting twins. I couldn't believe it! My partner Davey was unable to attend, so it was such a lot to take in.

"Then when I was 17 weeks pregnant, we found out our twins were suffering from TTTS."

TTTS is a rare but serious condition that can occur in 10-15% of twins that share a placenta.

Abbie said: "I will never forget my consultant stating, rather blatantly in fact that basically "your twins will either survive, you will lose one, have to choose between saving one, or lose both of them. That's how serious this condition is.

"Those first weeks were quite surreal, from the surprise pregnancy, to twins then for us to face the prospect of losing them to a condition we'd never heard of was really difficult to take in.

"My partner and family were so amazing and so supportive, but I still found it all a bit too much to deal with and my mental health suffered as a result."

Abbie was on her own when she was told about TTTS and what could happen. Her consultant drew a picture trying to explain the condition and said getting to 21 weeks would be good, but 28 weeks would be even better.

She found Twins Trust via Google and discovered all the information she needed to get through pregnancy and birth, plus information on TTTS.

"Finding other twin parents who had been through similar emotions was a real comfort and I felt we were not alone. We had found a community of support."

Abbie continued: "My care during pregnancy was good as I had scans every week. One twin was definitely smaller and they were concerned about me going into early labour. I was put on medication to try to stop this and given steroids for the girls' lungs.

"Week by week I was waiting for the scan result poised for something to happen. But I managed to pass the 28-week mark and at 32 weeks I was told Sofia was much smaller and had actually stopped growing.

"A decision was made at 34 weeks to deliver by emergency c-section which I was happy about as I'd been worrying ever since the news that she wasn't growing."

Sofia weighed 3lb 6 and Freya 4lb 5. Sofia was taken straight to the neonatal ward where she spent the first few days before being reunited with her sister.

"I felt so guilty that we weren't together those first days, Sofia had been robbed of being part of our family.

"But I am thankful that it was only a week until we brought the girls home together, in time for Christmas."

Both flourished when they were at home and Abbie started to look forward to going to baby groups and twins clubs at the start of 2020 – but the first lockdown meant that didn't happen.

"Like many new mums at that time, it was hard. My partner had to work, and our house was under renovation, so I moved in with my parents."

Now the girls are about to start nursery a couple of mornings and will celebrate their second birthday in December.

Abbie added: "They are our bundles of joy. I can see their development is slightly delayed but I think this is more to do with them being premature rather than TTTS and we expect them to catch up with other children in no time.

"I want to raise awareness of TTTS and show that the condition, whilst frightening, does not always lead to a bad outcome. We feel so lucky and blessed to have our two gorgeous girls.

"Research needs to continue into the condition, and I am glad to support Twins Trust in their bid to fund this. We have taken part in the annual walk for TTTS twice now and will continue to do so."

Shauna Leven, chief executive officer of Twins Trust, said: "On December 7, World TTTS Day helps raise awareness of this potentially serious, but often treatable condition.

"Everyone expecting twins or multiples should know the signs of TTTS and feel empowered to talk to their health care provider if they have concerns.

"At Twins Trust, we have resources to help parents like Abbie and Davey understand the condition, spot the symptoms and advocate for the care they need."

Notes to Journalists

For further information on multiple births please contact Beth Duffell bethduffell@twinstrust.org or pressoffice@twinstrust.org or call 01252 765985 / 07814 555917.

Twins Trust is the only UK-wide charity dedicated to improving the lives and wellbeing of families with twins, triplets or more. Representing 20,000 members and 100 local clubs in the UK, Twins Trust provides help and support to both parents and professionals to meet the unique challenges faced by multiple birth families. We invest in research to save lives, change lives and create better futures for multiple birth families. We also run a unique quality improvement project at Maternity Units to encourage and help with adherence to NICE QS46.

For further information, please visit www.twinstrust.org

Find out more information about TTTS here https://twinstrust.org/let-us-help/pregnancy-and-birth/finding-out/complications/ttts.html

- 1. Follow us on: Twitter/Facebook/Insta @twinstrust
- 2. For confidential and emotional support for families with multiples, please call Twinline which is staffed by trained volunteers that are parents of multiples and can offer support

on sleeping, feeding, crying, behaviour, discipline, school issues or special needs. It is free to call on 0800 138 0509 and is open Monday to Friday from 10am–1pm and from 7pm–10pm.