

News release

Friday December 3

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Three choices to save twins following TTTS diagnosis

At 26 weeks pregnant Deborah Johnston was told there was just a 33% chance that with treatment, her babies would make it because of the devastating condition, twin to twin transfusion syndrome (TTTS).

"We always knew there was a possibility of this as we'd been told about the condition at the first appointment with the consultant, but you just hope and pray it won't happen," said Deborah, who lives in Glasgow with partner Scott and daughter Rosie, aged four.

Doctors gave the parents-to-be three choices. They could do nothing but could face losing their twins, they could drain fluid but this might have only helped one twin or they could have laser surgery to give both babies a chance of survival.

Deborah added: "From very early on I was having more scans than I'd been used to with my daughter as I was told that it was a high-risk pregnancy. At one of my fortnightly scans, it became clear there was lots of fluid surrounding twin 2 and not as much around twin 1.

"Although I was very worried, I was reassured as everyone involved in our care from Wishaw General was keeping such a close eye on us and were so attentive.

"I then started having scans twice a week so they could monitor and check the fluid levels. The possibility of TTTS was obviously a real concern.

"I knew it was a serious condition, but I was advised not to Google this as it might not be helpful to me as I was already emotional and worried, so I took comfort in the fact I was being well looked after and tried to have faith in the process."

One day Deborah woke up and felt particularly awful. She could barely move and was incredibly uncomfortable. That same day Deborah had a routine scan at Wishaw Hospital.

"The staff were worried as there seemed to be no fluid at all around twin 1 and lots of fluid around twin 2. I was referred to the Queen Elizabeth Hospital in Glasgow and the next day Dr Janice Gibson examined me and said that my twins were very unwell, and their hearts and lungs were very poorly.

"She and her colleagues were so kind and explained everything to me. We were given three choices, do nothing, but there was a very high chance the twins would die; drain the fluid, but this might have only helped one twin, or have laser surgery to give them both a chance of survival.

"To us, the laser surgery was the best and only option as it gave us some hope; but it came with its own risks."

Deborah was 26 weeks +4 and the blood vessels were quite thick which makes the surgery much more difficult.

"Dr Gibson said there was a 33% chance both would make it and we clung onto that hope. The surgery was the only option for the boys. After the surgery I was told it had gone well and we had to wait overnight for a scan.

"The next day we heard two heartbeats – the relief was incredible; we were delighted but we were not out of the woods yet and we were told that the next few days would be critical while things settled. I was scared to move that weekend in case I went into early labour.

"During the surgery I also had fluid drained and once that had gone, I started to feel much better I hadn't realised how uncomfortable and sore I had been.

"From that point all the scans were much better with no more issues, this was great news as I was told the condition could come back which would mean early delivery.

"Physically I felt a lot stronger and more comfortable and it was great being able to spend quality time with my daughter and count down each week as it came and went. We were so happy when we made it to 36 weeks +4."

Deborah's twins Theo (4lb 6) and Olly (4lb 7) were born via a planned c-section, in Deborah's words "tiny and perfect".

They spent four days in neonatal care and then moved into special care for 10 days.

"They made great progress and we got to take them home in time for Christmas, it was the best present ever. We will be forever grateful for the care we received and to everyone who helped us on our journey.

"The past 18 months has been a rollercoaster but now I am delighted to be able to say I gave birth to the most wonderful twin boys during a pandemic and they survived TTTS!" Deborah added.

Helen Peck, Scottish coordinator for Twins Trust, said: "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.

"Twins Trust has resources to help parents 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

- 1. Follow us on: Twitter/Facebook/Insta @twinstrust
- 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.