



Keith Reed
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Tamba's Big Research Appeal: helping multiple birth families

Every day in the UK thousands of mothers bring their babies into the world – but at least one mother will see her multiple birth baby die.

Although many multiple birth families will have a normal pregnancy with a happy outcome, about half will have to spend time in a specialist or neonatal care unit and, although twins, triplets and more only represent about 1.5% of all pregnancies, they account for more than 7% of stillbirths and 14% of neonatal deaths.¹

At Tamba (Twins and Multiple Births Association) we don't believe that just because the risks and complications associated with multiple births are poorly understood we should accept that these babies are more likely to suffer complications or die.

As a charity we want to ask the difficult questions of those in power, highlight the flaws in the system and fund research to help improve the outcomes for multiple birth babies. Every baby has the right to a happy and healthy life; why should multiple birth families not enjoy those same basic rights? This is why in 2015 Tamba decided to do something about the imbalance. Numerous medical professionals were aware of urgent topics for multiple birth research that needed to be addressed – it just wasn't happening. When we launched the Big Research Appeal we were overwhelmed with the enthusiasm and support we received for this urgently needed funding for lifesaving and pioneering studies. Two years on, we are more than half way to our final goal of raising £60,000.

What is the Big Research Appeal?

Tamba launched the Big Research Appeal with four core ideals in mind:

1. Reduce the number of babies born too early.
2. Reduce the number of babies and parents enduring neonatal care.
3. Reduce stillbirths and neonatal deaths.
4. Improve treatments and survival rates for TTTS (twin to twin transfusion syndrome) babies and those with other multiple-specific conditions.

We promised to raise, with the help of our supporters, a minimum total of £60,000 to fund seven pieces of research. In Phase 1 we raised the first £20,000, which was matched by the British Maternal and Fetal Medicine Society (BMFMS). The Phase 1 money paid for three key pieces of medical research centred around single intra-

uterine fetal death in monochorionic twin pregnancies, neurodevelopmental outcomes in twin pregnancies with complications, and a study into the prevalence of monochorionic monoamniotic (MCMA) twin and triplet pregnancies.²

Phase 2 of the Big Research Appeal

In September 2016 we launched Phase 2 of our appeal. We were delighted to hear the BMFMS would once again be matching our fundraising efforts pound for pound. We're now just over the half way mark for this second round of fundraising, and indeed the overall project.

One of our priority areas for Phase 2 was cervical cerclage stitches in twin pregnancies. The stitch aids in cases of cervical incompetence when a weakened cervix can no longer sustain the growing weight of pregnancy, labour begins too quickly and this results in a pregnancy loss. Previous studies have been undertaken on cervical cerclage but most of these studies were primarily singleton pregnancies and only had a small number of twins; research into the effectiveness of cerclage in delaying labour in multiple pregnancies is greatly needed. The best way of understanding our motivation behind this is to share the story of where the stitch proved to be lifesaving.

Karen's story

"Twenty-three weeks into my first pregnancy, I woke to find my waters breaking. I was rushed into hospital but by then there was no fetal heartbeat. After four hours of labour, and unbelievable heartbreak, I delivered a perfect little boy. I was told the most likely reason I lost him was an incomplete cervix. I felt an unbearable guilt that my body had been unable to protect our little boy and it was my fault we lost him.

"A year later I discovered I was expecting twins. We were overjoyed but also filled with sadness and immense worry; if I couldn't carry one baby safely, how could I carry two? Our consultant monitored me closely with fortnightly cervical scans. I was terrified of losing these babies too and at the 22 week scan I was told my cervix was opening and my only option was a cervical stitch to close my cervix. We were told that despite a lot of research into cervical cerclage in single pregnancies, there wasn't much that looked at its success rate in multiple pregnancies. We decided to have the procedure anyway and the consultant told me my cervix was

so weak I would have lost my babies in hours.

“During the next few weeks one baby stopped growing and I had to have steroid injections. At 34 weeks the other twin stopped growing and I needed to have them delivered. My waters broke and I was taken to the delivery suite immediately and had the stitch cut. I gave birth to two beautiful girls – Holly (1.67kg) and Amelie (1.22kg). Despite being so little, they were alive and well. Any research that can help address the lack of knowledge in the area of cervical cerclage and multiple pregnancies is worth supporting to help stop parents from losing their babies.”

Phase 2 research grants

Tamba is delighted to announce that Dr Asma Khalil at St George's Hospital in London has successfully bid for funding to start a piece of research on cervical cerclage and multiple pregnancies. She will be performing a randomised controlled trial of emergency cerclage in twin pregnancies that are at imminent risk of preterm birth.

The second piece of research to be funded in Phase 2 will be undertaken by Dr Andrew Sharp at Liverpool Women's Hospital. He will be examining the myometrial transcriptome in twin pregnancy. Premature activation of uterine contractions underlies spontaneous preterm delivery. There is an urgent need for a better understanding of why twins are at high risk of preterm delivery. Dr Sharp and his team aim to use the study to identify and characterise key differences in the human myometrial transcriptome from singleton and twin pregnancies. The findings will be used to inform new therapeutic targets aimed at improving the management of preterm birth in multiple pregnancies.

Our families

Although this particular fundraising campaign is for a wide range of different research projects, it is important to remember who it will help – our multiple birth families. While the work is being done in hospital wards and university suites, the effects will be felt right across the country in the homes of twin and triplet families, and the multiple birth families of the future. Tamba is incredibly passionate about the Big Research Appeal. We're trying to create a world in which multiple birth families enjoy the same health



Holly and Amelie, delivered safe and well at 34 weeks' gestation.

benefits, resources and outcomes as any other family. This is perfectly summed up in our mission statement: Tamba is the only UK-wide charity working to improve the lives of twins, triplets or more, and their families. We do this through campaigning to improve health, wellbeing and developmental outcomes; funding clinical research to reduce the risks faced before, during and after birth; and by providing practical support and information for all families, including those in crisis.

References

1. **Tamba.** Latest ONS Figures Show Infant and Neonatal Mortality Rates Have Increased in England and Wales. [Online] available at: www.tamba.org.uk/document.doc?id=853 [Accessed 1 June 2017].
2. **Tamba.** First of Tamba's Big Research Appeal Projects Announced. [Online] available at: www.tamba.org.uk/big-research-appeal/projects [Accessed 1 June 2017].

To make a donation or to find out more about the **Big Research Appeal** visit www.tamba.org.uk/big-research-appeal

If you'd like to hold a fundraising event, and would like information or inspiration on how to help, email luciewigley@tamba.org.uk or call **01252 332344**.



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