



Kit Tarka Foundation

Preventing newborn baby deaths
through research & education

PRESS RELEASE

Bereaved parents launch charity to prevent newborn baby deaths

- Newborn baby boy Kit Tarka died on 29 September 2017. He was just 13 days old.
- He had contracted neonatal herpes (caused by HSV1 or the cold sore virus) whilst in the Royal Sussex Hospital in Brighton from an unknown source.
- Kit's bereaved parents Sarah Higson and James de Malplaquet have launched the Kit Tarka Foundation to prevent newborn baby deaths through research and education.
- A mini festival, featuring Fujiya and Miyagi and Alice Russell, will be held at St George's Church on 15 September 2018 to raise much needed funds.

Brighton parents of a baby who tragically died from neonatal herpes contracted at Brighton Hospital have today announced the line-up for a fundraising concert for the Kit Tarka Foundation (KTF), a new charity which aims to prevent newborn baby deaths through research and education.

KTF was established by Sarah Higson and James de Malplaquet after their son Kit Tarka died from neonatal herpes at just 13 days old. Neonatal herpes in Kit was caused by Herpes Simplex 1 (HSV1) or the common cold sore virus which Kit contracted when he was in the Royal Sussex Hospital in Brighton in September 2017 from an unknown source. The bereaved parents are determined to turn their family tragedy into a positive force for change.

Kit's mother, Sarah Higson, said "The experience we have gone through has caused us unbearable pain and and flipped our lives upside down. Kit was the perfect baby boy we dreamed of but we had to watch him die an agonising death and we will never see him grow into the wonderful child and adult we know he would be. We are now determined to do everything we can to stop any more families from suffering the way we are".

The charity have already reached their initial goal to raise enough funds to finance, with the help of Rockinghorse Children's Charity and the Chalk Cliff Trust, the first UK wide research project into neonatal herpes for over 25 years. Kit's father, James de Malplaquet said "we believe that until the true scope of the problem is known, the success of campaigning for awareness and change will be limited".

On 15 September, the day before Sarah and James should be celebrating Kit's first birthday, a mini festival, KitFest, will be held at St George's Church to raise funds for the foundation. A high profile line-up has been confirmed including Fujiya & Miyagi, Alice Russell & TM Juke, The Miserable Rich (featuring Kit's father James de Malplaquet), Gloria Cycles, We Bop Choir, Jess Bishop, artist David Shrigley as MC and 1BTN DJs Kerry Jean Lister (Feel Up) and



Kit Tarka Foundation

Preventing newborn baby deaths
through research & education

Señor Mick (Whiskey Preachin'). Tickets are £18 with a suggested £10 donation and are available via [Ticket Source](#).

Fujiya & Miyagi said "We are pleased to be able to support Kit's charity by playing the show on 15th September and hope the night can raise awareness of Neonatal HSV and help prevent it in the future. This will be our only Brighton show of the year. We hope to see lots of people there for such a worthwhile cause."

ENDS



Preventing newborn baby deaths
through research & education

NOTES FOR EDITORS

About Kit Tarka Foundation

The Kit Tarka Foundation (KTF) was established by Sarah Higson and James de Malplaquet after their son Kit Tarka died from neonatal herpes at just 13 days old.

KTF aims to prevent newborn baby deaths through research and education. We are determined to do all we can to prevent more families from going through the devastating tragedy Sarah and James have endured. Initial projects will focus on neonatal herpes but in the longer term, the aim is for KTF to fund projects relating to all causes of preventable neonatal death.

Our initial goal which has now been reached is to fund a research study into the prevalence and impact of neonatal herpes in the UK. The last UK wide published study based on actual cases uses data over 25 years old⁶ so the need for an-up-date study is glaring. This surveillance project will monitor the number of infections and mortalities from neonatal herpes in the whole of the UK and Ireland over 2 years and will be led jointly by Dr Katy Fidler of the Royal Alexandra Children's Hospital and Professor Paul Heath of St George's University of London Hospital. Approval of the project has been granted by the British Paediatric Surveillance Unit who will facilitate the research and the team are ready to go. There will also be a programme of education and training alongside the project to be initially trialled in Sussex. The project will commence in January 2019. The total project cost is £26,500 of which £5,000 is being funded by the Chalk Cliff Trust and £12,500 by Rockinghorse Children's Charity.

We believe that until the true scope of the problem is known, the success of campaigning for awareness and change will be limited.

About Neonatal Herpes

Neonatal herpes is a devastating virus which can ravage a new baby's body in a matter of days and, even if treated, can cause death or long term health problems such as brain damage or cerebral palsy. It is caused by the herpes simplex virus (HSV) which can be transmitted before, during or after birth from the mother or another individual in close contact with the baby. HSV was not suspected in Kit until it was too late so he never received the antivirals which would most likely have saved his life.

- **Every day in the UK 41 babies who were born alive die before they are 1 month old** and many of these deaths are preventable¹.
- The quality of neonatal (babies up to 1 month old) care in the UK has started getting worse – **a higher percentage of newborn babies died in the UK in 2016 compared with 2015**².



Kit Tarka Foundation

Preventing newborn baby deaths
through research & education

- **A baby born in the UK is more likely to die in its first month than a baby born in Cuba** or Latvia, nearly twice as likely than a baby born in Slovenia and nearly three times as likely than a baby born in Japan³.
- **70% of the UK population carry the herpes virus⁴ which can be fatal if passed to a newborn baby** – it is the same virus that can cause cold sores in adults - but many carriers have no symptoms and almost all are unaware how dangerous it can be for a baby.
- **One baby every week dies from neonatal herpes according to a localised study⁵**, but the current extent of the problem across the UK is currently unknown.
- The lack of knowledge amongst medical professionals around the transmission, recognition and treatment of neonatal herpes has caused the untimely death of many babies in the UK.

For more information and to read Kit Tarka's story please visit the Kit Tarka Foundation website: www.kittarkafoundation.org

How to Get Involved

Donate

Supporters can make a donation via the charity website <http://www.kittarkafoundation.org/get-involved>.

Fundraising gig

On 15 September, the day before Sarah and James should be celebrating Kit's first birthday, a mini festival, KitFest, will be held at St George's Church to raise funds for the foundation. A high profile line-up has been confirmed including Fujiya & Miyagi, Alice Russell & TM Juke, The Miserable Rich (featuring Kit's father James de Malplaquet), Gloria Cycles, We Bop Choir, Jess Bishop, artist David Shrigley as MC and 1BTN DJs Kerry Jean Lister (Feel Up) and Señor Mick (Whiskey Preachin'). There will be food stalls, bars and a raffle. Doors open at Tickets are £18 with a suggested £10 donation and are available via [Ticket Source](#).

Local businesses

KTF is looking for local businesses to support the above event. To find out about corporate sponsorship contact Susie Tempest at info@kittarkafoundation.org.

References:

1. Total neonatal deaths recorded in the UK in 2016 was 2,136 based on data from:
 - England and Wales: Office for National Statistics
 - Scotland: National Records of [Scotland](#)



Kit Tarka Foundation

Preventing newborn baby deaths
through research & education

- Northern Ireland: [Statistics and Research Agency](#)
- 2. In 2015, there were 2.72 neonatal deaths per 1,000 births; in 2017 there were 2.76 per 1,000 births; based on data from the above and the ONS dataset: [Births by mothers' usual area of residence in the UK](#)
- 3. UNICEF report: [Every child alive: The urgent need to end newborn deaths](#)
- 4. [BASHH](#): 70% of the UK population are infected with HSV1 or HSV2 by the time they are 25 years old
- 5. [Nottingham based study](#) found 17.5:100,000 babies were infected with HSV and over half of these die which leads to an estimated 66 babies dying per annum in the UK
- 6. The last published [full British study](#) into incidence rates was based on data collected from 1986-1991