

# National Media Kit



# About Tiny Tickers

Tiny Tickers is a small national charity that works to improve the chances of babies born with a serious heart condition. We want every baby with a serious heart condition to have the best chance of survival.

♥ One in every 125 babies is born with a heart problem but only around half of those are spotted during pregnancy.

♥ Over 1,000 newborns leave hospitals in the UK every year with no one realising they have a potentially life-threatening heart condition.

♥ Around 3,000 babies under one year old have heart surgery every year in the UK.

♥ Congenital Heart Disease (CHD) is the most common congenital birth defect and is one of the leading causes of deaths in infants under one year of age

♥ Some babies will die before anyone realises they have a poorly heart, or before getting the surgery that saves them.

Babies with undetected heart defects will often fall into the early stages of heart failure. Some will die before anyone realises they have a poorly heart, or before getting the surgery that would save them. We want to increase early detection rates of cardiac conditions thus improving a baby's chances of survival and long-term quality of life.

# What We Do

**Fund vital life-saving equipment** - not every heart condition can or will be diagnosed during pregnancy. By placing pulse oximetry machines in maternity wards we can provide another method of detection and ensure that the baby and family have access to the life-saving treatment they need before that baby experiences heart failure.

**Sonographer training** - Tiny Tickers is the sole provider of hands-on, hospital-based cardiac screening training for sonographers in the UK. Our training improves the prenatal detection of congenital heart defects using obstetric ultrasound at the '20 week' scan.

**Raising awareness** - our awareness campaign 'Think 20' informs and empowers parents-to-be about their 20-week scan; while 'Think HEART' raises awareness of the five potential signs of undiagnosed Congenital Heart Disease (CHD).

**Family Support** - we offer films and materials that help support parents and families dealing with a diagnosis. We also run a private online forum for heart families.

**Improving standards** - ensuring the voice of parents and the needs of babies are heard by those setting standards in CHD services.

# Our Impact

Our work delivers real life-saving results to heart babies, their families, and the health professionals that look after them\*



- 270 pulse oximetry machines placed at UK hospitals since 2017
- 1775 sonographers trained since 2016
- 28,000 information and awareness packs sent to GPs, health professionals and parents since 2016
- Over 100,000 views of our family support and awareness videos

\*figures correct as of November 2021

## A word from our CEO, Jon Arnold



Jon joined Tiny Tickers as Chief Executive in September 2013, after a career as a national media executive. He has extensive charity experience, including as a volunteer fundraiser and, for a number of years, as a trustee of a regional cardiac charity. He was the Chair of BBC Children in Need's northern committee (term completed November 2018), and a former parent representative on a regional congenital cardiac network steering group. Jon Arnold was inspired to join the charity by his experiences of having daughter, Zoe, with a serious heart condition.

"Zoe has changed my life. Zoe's story could have ended so differently. A combination of supreme medical skill, Andrea, my wife's instinct, and sheer blind luck means Zoe pulled through.

Tragically, for too many other babies, and their parents, the story doesn't have such a happy ending. Changing that for future generations is what inspires all of us at Tiny Tickers each and every day."



# We have many real-life stories available for interview







Ivy

**Every inch of her body was covered in a wire or a drain. Blood pots on the floor, tubes in her nose and mouth ~ Sam**

Ivy has Transposition of the Great Arteries, but unfortunately her condition was not picked up during pregnancy. At ten days old, her heart condition was eventually diagnosed when she was rushed into hospital. By that point she was in heart failure. Ivy spent her first Christmas in hospital, where open heart surgery saved her life. She's now a happy, energetic toddler. However, her mum Sam will never forget how close they came to losing her.

**I wrote to the sonographer to say thank you. We feel so lucky. We are very aware of how different it could have been. Tiny Tickers' work is so important ~ Ruth**

Ruth found out her baby had Transposition of the Great Arteries at her 20 week scan. Although devastated by the diagnosis, Ruth was directed to Tiny Tickers and was able to prepare for her baby's arrival with all the support and information she needed. Sebastian had open heart surgery at six days old and is now a happy nine month old baby. Without the early diagnosis, Sebastian may not be here today.



**Sebastian**



## **By the time we arrived at the children's A & E, she had completely collapsed ~ Shontele**

Yazmin's mum, Shontele, is painfully aware of how they almost lost their baby girl. Her condition, Coarctation of the Aorta, went undetected throughout Shontele's pregnancy. After birth, Yazmin began to deteriorate quickly. She slept all the time, refused to feed and developed a humming sound after every breath. Doctors attributed her jaundice to lack of feeding. When she was eventually rushed to hospital, it was almost too late.

Luckily, after the correct diagnosis and surgery, Yazmin has continued to go from strength to strength and is now a happy, six year-old girl.



# **Yazmin**



# Edie

**We will be forever grateful to the sonographer who spotted something wasn't quite right. Thanks to her, we had time to prepare for the "what ifs" ~ Jodie**

Edie was diagnosed with Tetralogy of Fallot during Jodie's pregnancy. Doctors told her that Edie may be blue and unresponsive at birth and for that reason a bed in NICU was on standby when she arrived. Her operation lasted six and a half hours and she was put on bypass twice, but six days later they took home a healthy baby with a repaired heart. Edie's early diagnosis meant she was able to have the care she needed as soon as she arrived, giving her the best chance of survival.

# Test for Tommy



Our 'Test for Tommy' campaign aims to ensure that every baby is given the test that could help save their life. It is a very simple test that could help identify newborn heart defects quickly and effectively, leading to immediate referral if required.

Low oxygen levels can be a key sign that a baby could have a critical heart defect. Research has shown that this simple, non-invasive newborn test could help identify cases of heart problems that would otherwise go undetected.

At present, pulse oximetry testing is not a mandatory newborn test within all NHS hospitals.





# Tommy

**I can never explain to someone the pain of losing your baby. It's a pain nobody wants to imagine or ever feel ~ Natasha**

Tommy was also born with Transposition of the Great Arteries, which sadly was not detected before his birth. When he was born, he displayed all the signs of heart failure that his mum, Natasha, now knows about – his skin was a blue colour, he didn't want to feed, he was always asleep and cold to touch. Natasha knew something was wrong and voiced her concerns to numerous medical professionals – but it was too late. Tragically, at 11 days old, Tommy passed away.

# CONGENITAL HEART DISEASE

CHD is when something goes wrong when a baby's heart is formed...

A baby is born in the UK with CHD roughly every 2 hours

Up to 1 in every 125 babies has some sort of heart defect

CHD is the most common congenital birth defect and causes up to 1 in 13 infant deaths



85% of babies born with CHD now survive into adulthood - that's more than ever before

Surgical survival rates in the UK are some of the best in the world - nearly 100% for some procedures

On average across the UK, nearly 50% of CHDs are spotted during pregnancy

## HOW TINY TICKERS HELPS...

### TRAINING

Specialist training for sonographers providing 20wk pregnancy scans

### AWARENESS

Spreading the signs of undetected CHD in newborns to new parents and health professionals

### SUPPORT

Helping families who are affected by CHD

### EQUIPMENT

Providing machines that help detect CHD in newborns

### STANDARDS

Campaigning to improve standards of CHD services

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