Serious heart conditions not detected because of lack of pulse oximetry testing

Monday 29 July, 2019

A recent review undertaken by NHS England recommended to the UK National Screening Committee (UK NSC) **against** using pulse oximetry as an additional test in the newborn and infant physical exam (NIPE).

Pulse oximetry screening is a safe, painless and simple test that has been shown, in research studies involving almost half a million babies, to identify babies with life-threatening heart defects (critical congenital heart defects or CCHD) before they become seriously unwell.

Poppy's story

Told by her mother Krystal

"When Poppy was born, her father Kelvin and I were concerned because she was a blue shade in colour but the midwives assured us that this was because she was born outside and was probably cold, (she was born in the car at the hospital car park). She wasn't given a routine pulse-oximetry test which would have picked up that her oxygen levels were low. A junior doctor examined her and said she was fine.

"For 36 hours Kelvin and I expressed our concerns about her colour and were told we were anxious parents and that she was cold because we hadn't done "skin to skin" with her. Finally, a senior doctor took us seriously and a pulse oximetry test was taken, it showed that her oxygen levels were only 38 percent and that her heart was racing. A second test with a different machine showed the same result. Shortly after this, Poppy stopped breathing and had to be resuscitated.

"We were sent to the Evelina hospital as it was thought the problem could be heart related. Many hours later we received the worrying news that Poppy had TGA (Transposition of the Great Arteries), a serious but treatable heart condition. At one-week old Poppy received her life-saving surgery.

"The operation went well. Poppy is now enjoying school and is a Brownie, she likes to tell the other children about her heart condition and explain why she has a scar.

*"If a **pulse oximetry** test had been taken when Poppy was born, I feel she could have been treated earlier rather than getting to the stage of needing resuscitation. The argument against including pulse oximetry in the new-born screening programme is that medical staff will notice the vital signs and give a test if needed; this clearly was not the case where Poppy was concerned."*

Elio's story

Michael Fragnito from Great Baddow, near Chelmsford, tells the story of the short life of his son Elio and how pulse-oximetry could have saved him.

"On Wednesday 4th July 2018, my wife Sarah gave birth to our second child, a brother for our daughter Elena, Elio was born via c-section and the procedure itself was a success.

"However, we had concerns about Elio as he had very little interest in his bottle and appeared particularly sleepy and floppy, his skin had a slightly blue tinge and at times he felt cold and clammy to touch. Sarah asked if she could stay at the hospital another night.

"Despite querying these concerns with the midwives, we were reassured that this was quite normal and nothing to worry about. But during that second night Elio collapsed and was rushed to intensive care.

"The consultant informed us that there were issues with Elio's heart and an Echo scan resulted in a diagnosis of Hypoplastic Left Heart Syndrome (HLHS).

"We spent the next five weeks at Great Ormond Street Hospital but despite their best efforts, Elio was unable to recover well enough to go through the first stage of surgery (Norwood procedure). He passed

Media:





Related Sectors:

Charities & non-profits :: Children & Teenagers :: Health :: Lifestyle & Relationships :: Medical & Pharmaceutical :: Public Sector & Legal :: Women & Beauty ::

Related Keywords:

Chd :: Heart Conditions :: Baby Screening :: NHS :: Pulse Oximetry :: New Born :: Congenital Heart Disease :: Early Diagnosis :: Health Test :: Pulse Oximeter :: NIPE ::

Scan Me:

away on 9th August 2018.

“We firmly believe that this level of distress could have been prevented if a pulse oximetry test had been taken as this would have shown that his oxygen levels were dangerously low.

“Had this been picked up sooner, Elio's collapse would have been prevented and the Norwood procedure could have been undertaken and our son would probably still be alive today.

“I strongly believe that pulse oximetry should be a test given to all new-borns as the staff did not pick up on the vital signs that Elio had a heart condition, despite our concerns. NHS England is recommending that “clinical judgement” be used to decide if a pulse oximetry test is needed, but Elio’s case shows that judgement is not always correct. This test that takes a couple of minutes could have saved our son’s life.”

The national screening committee is holding a public consultation on whether the evidence presented supports the decision. Anyone can make their views heard by responding to the consultation by August 9th.

The Children’s Heart Federation and other charities Tiny Tickers, Little Hearts Matter and Young at Heart are encouraging parents like the Aveling and Fragnito families to tell the public consultation their experiences.

Further information

Krystal Aveling wants to tell Poppy’s pulse oximetry story on television, radio or in print.

Michael Fragnito wants to tell Elio’s pulse oximetry story in print.

If you would like to interview Krystal Aveling or Michael Fragnito or would like further information about pulse oximetry, email Joanna Heath joannah@chfed.org.uk or phone 0300 561 0065 mobile 07946019876

About the public consultation

https://legacyscreening.phe.org.uk/pulse-oximetry

About pulse oximetry

http://www.chfed.org.uk/campaigns/chf-pulse-oximetry-campaign/

http://www.chfed.org.uk/poppys-story/

http://www.chfed.org.uk/indis-story/

About the Children’s Heart Federation

CHF is the leading UK children’s heart charity and works with individuals and organizations concerned with children and young people with health and educational needs due to acquired or congenital heart conditions.

CHF was registered with the Charity Commission in 1988 and is administered and managed by a board of trustees.

www.chfed.org.uk

Company Contact: