



Little Hearts Matter

UK National Screening Committee
PHE Screening
Floor 5
Wellington House
133-155 Waterloo Road
London SE1 8UG

6th August 2019

Dear UKNSC

Re: Pulse-oximetry Screening for Critical Congenital Heart Defects NSC Consultation

As the representative of over 5800 members, all affected by single ventricle heart disease, I am writing to contribute the Little Hearts Matter response to the request for more information to support the introduction of Oxygen Saturation Screening in the neonatal period. I am submitting my response by letter as the provided consultation pro-forma does not allow for comment or expansion of any of the issues that need exploring as part of the consultation.

New Born Screening

“Your newborn baby will be offered some screening tests in their first 6 to 8 weeks.

Most babies are healthy and won't have any of the conditions the screening tests are looking for.

But for those babies who do have a health problem, the benefits of screening can be enormous.

Early treatment can improve their health and prevent severe disability or even death.

The screening tests are quick and simple, and won't harm your baby in any way.

It is recommended that your baby has the tests, but you can decline them if you wish.”

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Supporting every step of the half a heart journey

75 Harborne Road, 4th Floor, Edgbaston, Birmingham, B15 3BU **T:** 0121 455 8982 | **E:** info@lhm.org.uk | **W:** www.lhm.org.uk
President: Baroness Valerie Howarth of Breckland OBE **Vice-Presidents:** Mr William J Brawn CBE MBBS FRCS FRACS, Mr Andrew C Shaw BSc FCA CTA FRSA

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I will use your reasons for not introducing O₂ Saturation Screening to highlight Little Hearts Matters comments.

“For babies with CHD or other non-cardiac conditions it is not clear that investigations and identification of these conditions will lead to any better outcome than a diagnosis at the time the baby becomes symptomatic.”

Undiagnosed complex heart conditions can result in the death or serious brain damage of a child with a single ventricle heart condition after birth. Little Hearts Matter has a number of members that have experienced the loss of their child before a diagnosis was made. They were discharged home, collapsed and died before a diagnosis was made.

Currently only 53% of CCHD is diagnosed before birth and even though single ventricle heart conditions make up a large proportion of conditions diagnosed it does not, and will not, provide a 100% detection rate in the near future.

6 hourly discharge has led to newly delivered babies being discharged into the community before any symptoms of CHD can be seen, non-detection from standard tests has led to collapsed children at home, emergency admission and poor short and long term outcomes in this complex patient group.

“A positive result from pulse oximetry will generate some harm including: parental anxiety, a longer stay in hospital, possible transfer to the neonatal unit, further tests to assess for non-symptomatic conditions.”

Having set out **your** NHS statement above re the need for neonatal screening this O₂ Saturation test decision statement is extraordinary. All neonatal tests could create the need for a longer stay in hospital, a higher degree of investigation and careful consideration of the results. Your conclusion that it would cause a greater concern for this group of parents rather than any other is inaccurate and discriminatory. One could suggest that no neonatal screening should be offered if this was the reason given to exclude testing.

As an organisation that works with families at all stages of diagnosis and with parents who seek further investigations for subsequent pregnancies, after a CCHD diagnosis in a previous child, we know that if tests are explained correctly and the results are described correctly parents are grateful that all possible outcomes have been explored, even if the test has shown a false negative.

As O₂ Saturation testing is non invasive, unlike the spot test that detects complex but much rarer conditions, 1 in 10,000 children have PKU, 1 in 4,000 children have Cystic Fibrosis, and it is a test that has been supported by midwifery teams and is now part of routine testing across the US, it is extraordinary that it has caused such a debate in the UK. Are the 1 in 136 (145 from BHF) children with a congenital heart condition, or the 25% of those who have a complex cyanotic condition that would need prompt, if not urgent, treatment after birth not as important?

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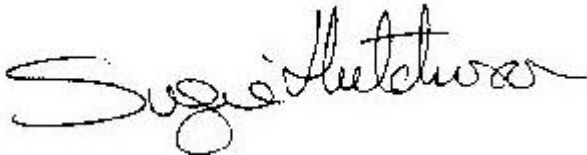
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O₂ Saturation testing kits are not expensive. They provide a non-invasive and mainly accurate test when seeking out cyanotic heart conditions and, as a sub-set, other respiratory conditions. Our parents test their diagnosed children at home with SATS monitors so it is clear that testing does not require high levels of medical training. Inclusion of this test in the Neonatal Screening portfolio across the UK would be beneficial for any child with CCHD and other children with previously undetected respiratory conditions.

Little Hearts Matter welcomes a further opportunity to contribute to this most recent consultation and urges you to reconsider your proposal not to include this simple and easily administered test.

On a personal note I look to you to create every opportunity for a diagnosis of CCHD to be made, before and after birth. Screening allows for informed decision making and better outcomes, not just survival, for the children. I don't like my first contact with a family to follow the death of their child because they have collapsed at home and not been in time for any treatment. Sadly often the diagnosis of a single ventricle heart condition then comes as the result of their baby's post-mortem.

Yours sincerely

A handwritten signature in black ink that reads "Suzie Hutchinson". The signature is written in a cursive, flowing style.

**Suzie Hutchinson RGN; RSCN
Chief Executive**

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