

20,000 Midland Mums needed to join Largest Heart Screening Study for Newborn Babies

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Researchers from the University of Birmingham and Birmingham Women's Hospital are asking mums from across the Midlands to sign up for the largest ever study looking at screening new born babies for congenital heart problems.

On the eve of Mothering Sunday, the University is hosting a major event at the Bullring shopping centre on Saturday March 1st (between 12-4pm) to encourage mums-to-be to become involved in the trial.

The team eventually hopes to recruit more than 20,000 mothers and their babies from across the Midlands over the next year. The six NHS trusts involved in the research cover an area that includes Birmingham, Wolverhampton, Warwickshire and Shropshire.

The PulseOx study will test whether using a simple test to measure blood oxygen levels in all newborn babies can cut the number of deaths from congenital heart disease.

Midwives across the region will use pulse oximetry, which measures levels of oxygen in the blood using a small sensor attached to the newborn baby's hand or foot. Babies with low oxygen levels may be more at risk from heart disease.

Congenital heart disease occurs in around 1 in 125 births in the UK and remains a major cause of death in newborns.

Current screening involves a routine examination for all newborn babies, usually in the first 24 hours after birth, which includes an assessment of the heart function. However, the researchers believe that over half the babies who have congenital heart disease will not be picked up by this examination.

Lead investigator Dr Andy Ewer comments: "We already know that low levels of oxygen in a baby's blood can be a sign of problems with the heart. We really want to see whether by using this simple test we are able to pick up newborn babies who have congenital heart problems before they develop symptoms. This is a simple, painless test that takes no more than a few minutes. We would really like to encourage mothers across the Midlands to become involved in the study because, thanks to advances in treating heart defects, there is potentially a significant benefit in picking up these problems at an early stage."

Debra Bailey's son Jason was born with congenital heart problems: "Jason was born with a number of serious heart problems, for example his heart is on the right hand side of his chest, but unfortunately he was not diagnosed until he was nearly four months old. What we were not expecting was the severity of his condition, and Jason underwent his first open heart surgery the day after he was diagnosed. The affect of being told that your child has a life threatening condition is a feeling you cannot put into words. I am absolutely convinced that if the pulse oximetry test had been available at Jason's birth he would have been able to receive his treatment immediately and we would have been able to come to terms with the situation a lot sooner."

Professor Khalid Khan adds: "With the support of hospitals and mothers across the Midlands we will be able to get a real idea of how we can best use this test in the health service to benefit mothers and their newborns."

For further information contact: Ben Hill Press Officer, University of Birmingham, Tel 0121 414 5134, Mob 07789 921163, email b.r.hill@bham.ac.uk

Professional images of an infant receiving a Pulse Oximetry test are available on request. Dr Andy Ewer is available for interview.

ENDS

Case Study – Debra Bailey

My name is Debra Bailey I am married with 3 children all boys, Stephen who is 15, Jason who is 13 and Aaron who is 9 and we live in Birmingham.

I am also the current Vice Chair for a very special voluntary charity called Young at Heart which is run by parents of children born with heart conditions. Young at Heart is the support group for the Birmingham Children's Hospital Cardiac Unit.

Jason was born in February 1995 by caesarean section. He was born with several different heart defects, his heart is on the right hand side of his chest, but unfortunately Jason was not diagnosed until he was 4 months old.

What we were not expecting was the severity of his condition, Jason underwent his first open heart surgery the next day. We felt as if our world had fallen apart and we were totally devastated. Our lives would never be the same again. The affect of being told that your child has a life threatening condition is a feeling you cannot put into words.

Jason has since received two further open heart operations and several cardiac catheterisations, he has experienced serious problems, and at one point we were told that he may not pull through, but with the expertise of the surgeons and dedicated staff at Birmingham Children's Hospital and Jason's strong will he is now 13 years old.

Jason's surgery was only palliative and his cardiac condition can never be corrected. We have been told that he will need a heart transplant. Jason's future is very uncertain and we have been through some very difficult times, he does struggle with daily life but we take each day as it comes and try to encourage him to lead as normal life as possible. It is extremely hard sometimes when your child looks to you to make things right and when you can't it takes every ounce of strength you have to be strong and not show you're scared too.

It is not all doom and gloom - we have had some fantastic experiences and we have some lovely memories, and I can safely say that I value life more than I ever did.

Early detection through this type of non-invasive screening should improve the outcome of babies born with congenital heart conditions by allowing the relevant health professionals, along with the parents, to make decisions and act accordingly.

I can speak from first hand experience, and I am absolutely convinced that if the pulse oximetry test had been available at Jason's birth he would have been able to receive his treatment immediately and therefore we would also have been able to come to terms with the situation a lot sooner.

NOTES TO EDITORS

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Birmingham is a centre of research excellence. Its research has been impacting on people's lives for more than a century and it continues to lead the way in breakthroughs and innovations. These include:

1937 creating vitamin C tablets 2008 developing cancer vaccines

1912 first UK course in oil mining 2008 cleaner fuels

1960 Developing pacemakers 2008 tackling global obesity

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The University plays an integral role in the economic, social and cultural growth of local and regional communities; working closely with businesses and organisations, employing approximately 6,000 staff and providing 10,000 graduates annually. The University contributes £662 million to the City of Birmingham and £779 million to the West Midlands region, with an annual income of more than £388.6 million. In 2005, new graduates accounted for almost 60% of the new workers in the City with a degree or higher level qualification. 44 % of our graduates take up their first employment in the Region.

Pulse Ox study

For more information about the Pulse Ox study visit the website: <http://www.pulseox.bham.ac.uk> (<http://www.pulseox.bham.ac.uk>)

The six participating centres are:

- Birmingham Women's Hospital
- Heart of England NHS Foundation Trust
- City Hospital (Sandwell and West Birmingham NHS Trust)
- New Cross Hospital (The Royal Wolverhampton Hospitals NHS Trust)
- Royal Shrewsbury Hospital (The Shrewsbury and Telford Hospital NHS Trust)
- Coventry and Warwickshire Hospitals

Pulse Ox Promotional event at the Bullring – 1 March 2008, 12noon to 4pm

Rotunda Square at the Bullring - Researchers from the University of Birmingham and Birmingham Women's Hospital are asking for mums-to-be from across the Midlands to sign up for the study which will screen new born babies for congenital heart problems. This simple test, named PulseOx, will measure blood oxygen levels using a small sensor attached to the baby's hand or foot.

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