



Children's Heart Study

Paediatric Cardiac Surgery Study

Volume 1, Issue 2

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This study aims to select, define and measure the complications that may follow cardiac surgery and that have the most impact on patients and families

INSIDE THIS ISSUE

Update on Phase 1 of the study and the BDA	1
Re-cap on what we are doing now	2
How is the study going	3
What the families taking part say	2-3
Message from our Birmingham team	4
Colouring picture	5
How to contact us	5

Phase 1: Brief Developmental Assessment, 'BDA' – publications

A **BIG** thank you again to **the 1200 families** who took part in the first phase of the study, which finished in August last year.

The data from all the assessments has now been analysed and we are very pleased to say that the Brief Developmental Assessment is a valid tool for picking up on possible developmental delay in children between the ages of 4 months and 5 years. The results of the study are currently being peer reviewed (reviewed by independent experts); if the review process



completes successfully we then plan to introduce the BDA as an initial assessment tool for children undergoing cardiac interventions. Unfortunately the BDA was not valid in the youngest age group (babies under 4 months); therefore further research is needed to determine the best

approach to assess the youngest children.

Any families wishing to read a copy of the research articles once they have been accepted for publication please email us at children.heart@gosh.nhs.uk and we will email you a copy.

Before we introduce the BDA....

We are in the process of developing clear guidelines to follow when using the BDA that are supported by a large range of health professionals and parents. We are surveying 75 health professionals with different backgrounds and expert parents; and asking them to give their comments on the process that should be followed if the BDA flags up any possible developmental issues with a child (i.e. an amber or red result in any area assessed). The results of this survey will be submitted for peer review and hopefully published later this year. An update on this will be given in our next newsletter.

Phase 2: Incidence and Impact Study – reminder of what we are doing

"...we are asking parents if we can stay in touch for 6 months after the initial operation to record the impact"

Phase 2 of the Children's Heart Study is taking place in five UK hospitals: [Great Ormond Street Hospital](#), [Bristol Royal Hospital for Children](#), [Evelina London Children's Hospital](#), [Birmingham Children's Hospital](#), and [The Royal Hospital for Children, Glasgow](#). The study is looking to see how often any of nine types of complication happen after heart surgery in children (this is called *incidence*) and how much these complications effect the child and family (the *impact*). We are looking at how often these complications happen in all children who have surgery at each of the five hospitals over 18 months. We are asking

parents of children with complications as well as a comparison group of children without complications if we can stay in touch for 6 months after the initial operation to record the impact. We are measuring quality of life for both the child and family, what happens clinically to the child over the 6 months after surgery, how many days the child has to be in hospital and whether there were financial burdens on the family from caring for the child (for instance if one or both parents had to give up work). We are measuring these aspects 4 times – at discharge from hospital and then 6 weeks, 3 months and 6

months after surgery. At the end of the study, we will have a much better idea of what the most common complications are and what they mean for the child and their family. This will mean that we can then plan and test ways to reduce both the occurrence and the impact of these complications. It also means doctors can provide families with much better information about what the future might hold before their child has an operation.



"We recently took part in the Children's Heart Study, I think this study is really important to help improve or streamline future treatments if possible.

I found the follow up questions (be it on the phone or in person) with Sheryl really easy going, it helped to talk through how I was feeling and what was going on."

Parents of Madison

How is the study going?

Recruitment for the incidence and impact study started a year ago now and once again we have received a great response from families wishing to help. In the last year we have studied the data of 2327 children that have had surgery across the country! Out of these children, **448 families** have agreed to be followed for 6 months. Recruitment to the study will continue until May 2017, and we are hoping to have followed around 750 families by the end of 2017.

Hospitals taking part in the study	Number of families recruited so far*
Birmingham Children's Hospital	101
Bristol Royal Hospital for Children	77
Evelina London Children's Hospital (GSTT)	77
Great Ormond Street Hospital	128
The Royal Hospital for Children, Glasgow	65

*Until & inclusive of November 2016



"Having the opportunity to be a part of the G.O.S.H research study has not only been the chance for us to give something back to an organisation that saved our son's life, but also a welcomed opportunity to reflect and take stock of where we are and how we are moving forward and coping with our son's condition.

Throughout the process of gathering our data, Jordana has always been understanding, empathetic and helpful and made the often monotonous task of question and answer sessions seem more like talking to a friend.

It has been a very personable experience that will hopefully continue the extraordinary work that already goes on at G.O.S.H. Rest assured should there be any future case studies required...we will be more than happy to help."

Parents of Cassius



"...a welcomed opportunity to reflect and take stock of where we are and how we are moving forward..."

A message from the Birmingham team...

Here at Birmingham Children's Hospital our 4 cardiac surgeons carry out just under 500 children's heart operations every year. Our paediatric intensive care unit is a busy 31-bedded department looking after patients with a wide variety of health problems including complex cardiac conditions.



BCH Children's Heart Study Team: Jenna, Sinead & Alison

"We have learned a lot about our patients' journeys and look forward to putting this new knowledge to good use in the future..."

We were very excited to be asked to be involved in the Children's Heart Study. It is crucial that children's hospitals around the country work together to conduct research that can potentially improve the care and treatment our patients receive. This project provides a new opportunity for families to share their experiences, not only of having a heart operation,

We have learned a lot about our patients' journeys and look forward to putting this new knowledge to good use in the future to improve the care we provide. It is the first time that this type of information has been collected nationally and it is our hope that the findings will influence future children's heart research.

The study is not without its challenges both for the research team and the families taking part. It's busy, with lots of patients to monitor and interview every day. We listen to parents who are willing to share their stories through the highs and lows of their health care experience.

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Anyone wishing to read in more detail about this study follow these links:

<http://www.nets.nihr.ac.uk/projects/hsdr/12500506>
<http://www.gosh.nhs.uk/medical-information/clinical-specialties/cardi thoracic-surgery-information-parents-and-visitors/why-we-do-research/complications-after-heart-surgery-children>

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