



**W**ELCOME to 6th edition of the Expanded Newborn Screening newsletter. We now have completed the first 9 months of the study. This newsletter will review the data collected so far. The study would not have been a success without all the hard work and input from the participating teams. We thought it was about time that you get to know some of them better so are starting a regular feature to introduce our teams starting with Guy's St Thomas'. We hope you enjoy it!

## The number of screen positive, true positive and false positive cases:

In the last month there has been just one more false positive case of IVA and therefore there is little to report on the cases. The numbers are shown below:

Condition	Screen positives	True positives	False positives
GA1	3	3	0
HCU	1	1	0
IVA	12	3	9
LCHADD	0	0	0
MSUD	2	1	1
<b>Total</b>	<b>18</b>	<b>8</b>	<b>10</b>

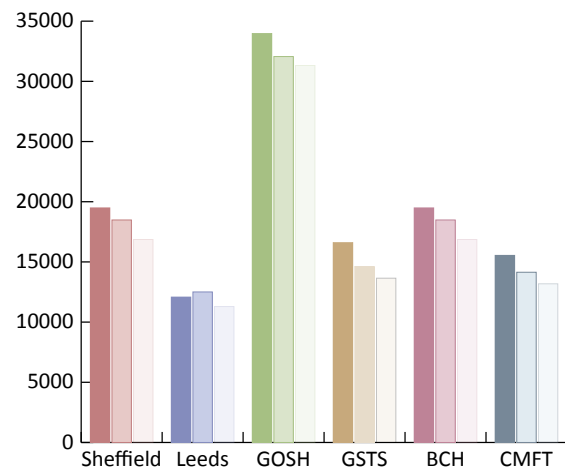
## The number of declines:

The number of declines has continued to decrease month on month throughout the study. During the third quarter the overall decline rate was just 0.02%. This is a fifth of that seen in the first quarter. Sheffield's decline rate is still a little higher than other areas but throughout the study has decreased from 0.20% to 0.06% showing improvements in acceptance. The low number of declines that has persisted throughout the pilot shows really good acceptance of the expanded screening programme by both professionals and parents. (The table right shows the number and the percentage of declines calculated based on number of cases at site).

## The number of births:

Over the 9 months of the pilot, we have seen a total of 332,004 births. The numbers of births in each centre has fallen slightly each quarter (see graph), however, we think that we are still on track for the predicted 430,000 births over the course of the year.

The graph below depicts the number of births by centre during the 1st, 2nd and 3rd quarters. (Abbreviations: GOSH: Great Ormond Street Hospital, GSTS: Guy's St Thomas', BCH = Birmingham Children's Hospital, CMFT = Central Manchester Foundation Trust)



Site	Q1	Q2	Q3	Declines by site
BCH	23 (0.12%)	9 (0.05%)	1(0.01%)	33 (0.06%)
GOSH	36 (0.11%)	12 (0.04%)	8 (0.03%)	56 (0.06%)
GSTS	4 (0.02%)	3 (0.02%)	0 (0.00%)	7 (0.02%)
Leeds	3 (0.02%)	2 (0.02%)	0 (0.00%)	5 (0.01%)
CMFT	18 (0.12%)	13 (0.09%)	6 (0.05%)	37 (0.09%)
Sheffield	38 (0.20%)	12 (0.06%)	10 (0.06%)	60 (0.11%)
<b>Declines by quarter</b>	<b>122 (0.10%)</b>	<b>51 (0.05%)</b>	<b>25 (0.02%)</b>	<b>198 (0.06%)</b>

## Communication Study:

Identifying babies with one of the five rare conditions is a two stage process. During the newborn screening, the tests identify babies with a raised metabolite (chemical in the blood) which may indicate that the child has one of the conditions. These cases are called screen positive. When a screen positive diagnosis is received, the parents are contacted by the clinical team to explain the results of the test, provide treatment as necessary and complete further testing to confirm a diagnosis. Dependent on the test required, this may take up to a week, and is often, understandably, a period of worry for the parents. We are undertaking research to explore the interaction and communication between the clinical team and parents at the time of a positive screening result. Previous research has looked at the impact of screening results on parents and families, but there is little work looking at the effect of the information and communication, and how this can be best managed to meet parental need, and minimise the emotional impact. Based on experiences during the Expanded Newborn Screening Programme, this study will explore the views of parents whose child received a screen positive result, and of the Metabolic Physicians, Dieticians and Nurses involved across the 6 sites. It will investigate the best approach to and timing of communication with parents. The information collected will be used to develop recommendations regarding the communication of screen positive results to minimise the impact on the families concerned. The research is being funded by Sheffield Hospitals Charities Trust and is organised by Dr. Louise Moody, Coventry University in collaboration with Professor Jim Bonham, Expanded Screening Project and the Collaborations for Leadership in Applied Health Research and Care for South Yorkshire (CLAHRC-SY). It is planned to carry out the interviews between June and December 2013. Ethical approval has been granted and local research governance approvals are currently being sought for each site to allow the interviews to begin. For more information, please contact:

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The Guy's St Thomas' laboratory group and Evelina Clinical Team posing for us in the sunshine including **Ian Hutton** (centre back) who has agreed not to cut his hair for the duration of the expanded screening project!

## Meet the Team at Guy's St Thomas':

We asked the team to give their opinions on the expanded screening project. They recognised the potential benefits of expanded screening, and the importance of collaborative working in screening: *"Expanded newborn screening has made a huge difference to the families where we have made early diagnosis of treatable metabolic disease. The collaborative approach taken in this pilot, both between the laboratories and also clinical teams, midwifery units etc., has been successful in building up the evidence needed to inform national policy."* **Fiona Carragher**, Laboratory Director of Newborn Screening- South East Thames Region.

**Rachel Carling**, Consultant Scientist and Deputy Director said

*"I am particularly interested in the analytical aspects of expanded newborn screening and I am pleased that the laboratories involved in the pilot scheme are working together to further improve the quality of the results."*

The team also recognised the importance of completing a robust pilot:

*"I endorse the more conservative approach to the expansion of the newborn screening testing panel which we have adopted so far in the UK"* **Wyn Griffiths**, Lead Clinical Scientist, SE Thames NBS Laboratory, GSTS Pathology.

The team also provided information on their wishes for newborn screening in the future. **Kate John**, Operational Manager, was hopeful that the screening programme would be further expanded to test for more conditions.

(If you want your team to be featured in our next newsletter, please contact us).

## Update on leaflets:

In the April addition of the newsletter, we reported that updated leaflets were now available from Harlow printing. Please only contact Harlow if your organisation is participating in the pilot. Written and verbal translations, are now available for download from the website.

We want your feedback and comments! We want this newsletter to be useful and interesting to you. Please provide feedback and any information that you would like including in the newsletter via the website:

<http://tinyurl.com/cjwg8nh>



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