

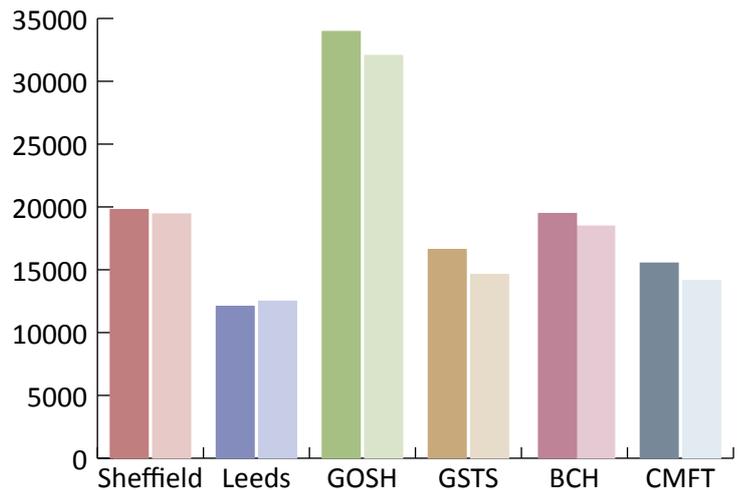


**W**ELCOME to the 4th edition of the Expanded Newborn Screening newsletter. The pilot has now been active for more than 6 months. As such, this newsletter will focus on the review of the results so far compared with our projections for this point. We hope you enjoy it!

## The Number of Births:

After the 1st quarter, we reported an increase in the number of births compared with what would have been expected in that time period. However, the number of births fell a little in the 2nd quarter meaning that we may be closer to predicted 430,000 births at the end of the one year period than previously anticipated.

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



## The Number of Declines:

The total number of declines in the first six months of the pilot was 173. This is just 0.076% of the total number of births. 70% of these declines occurred in the first quarter, the number of declines falling sharply in the 2nd quarter. This reveals excellent acceptance of the expanded programme by mothers and a great achievement by the midwives in encouraging mothers to participate. The number of declines still remains a little higher in Sheffield compared to other sites. Leeds & GSTS have lowest decline rates.

Site	1st Quarter	2nd Quarter	Total Declines at sites	% based on number of births at site
BCH	23	9	32	0.084
GOSH	36	12	48	0.072
GSTS	4	3	7	0.022
Leeds	3	2	5	0.020
CMFT	18	13	31	0.104
Sheffield	38	12	50	0.131
<b>Total Declines</b>	<b>122</b>	<b>51</b>	<b>173</b>	

## The number of Screen Positive, True Positive and False Positive Cases:

Over the year pilot it is predicted that we would identify 41 screen positives of which 16 would be true positives and 25 false positives.

During the first six months of the pilot, 13 screen positive cases have been identified, 6 of which were true positives including cases of IVA, GA1 and MSUD.

The number of true positives is in line with what we would have predicted at this point in the pilot. For all conditions except IVA, the numbers of false positive cases are lower than expected.

The number of screen positive cases of IVA are a little higher than anticipated, and the true positive cases identified through screening so far are mild. Further work may need to be undertaken to define the IVA cases, and a workshop is being planned for later in the year to discuss this with international colleagues who may have experience of this.

## What's in store for the next newsletter?

The March edition of the newsletter will provide details on research process and how will data will be collected from each of the participating centres.

Scan this QR code with your smart phone to connect directly to the ENBS website.



## New Short Films and Website for Rare Diseases Day:

The 28th February 2013 marks Rare Diseases Day. During the last three months, the Expanded Newborn Screening Project Group have commissioned Optical Jukebox to prepare a suite of new films exploring screening and what is like to live with one of the rare conditions. These have been produced in association with Sheffield Children's NHS Foundation Trust, Birmingham Children's Hospital NHS Foundation Trust, Sheffield Teaching Hospitals NHS Foundation, CLIMB & Rare Disease UK. These will be available on the new expanded screening website, developed by Black Cat Websites in collaboration with the project group at the end of February. The six films and the new website will be launched at the Rare Diseases Parliamentary Reception on 27th February 2013.



We want your feedback and comments! We want this newsletter to be useful and interesting to you. Please provide feedback on any information that you would like to be included in the next newsletter, any ideas you may have for the website etc. etc. Please contact via the website at <http://www.expandedscreening.org/home/contact.asp>

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