



WELCOME to the 11th Expanded Newborn Screening newsletter. We have compiled a report from the Expanded Newborn Screening evaluation, and have passed this on to the National Screening Committee (NSC) for their consideration. The NSC met on 21 November 2013 and discussed the project and conditions. They are supportive of the inclusion of three of the conditions (glutaric aciduria type 1, homocystinuria (pyridoxine unresponsive) and maple syrup urine disease) in the national screening programme in England. They have opened a public consultation for all five conditions, so please add your views by 20 March 2014:

<http://www.screening.nhs.uk/bloodspot-consultation>

As always, thank you for your ongoing commitment to this project, and congratulations to all for what we've achieved so far!

What will happen now?

The NSC's consultation closes on 20 March 2014, after which they will consider the responses, and provide a recommendation to Ministers regarding which conditions they think should be included in the national newborn screening programme in the future. The Ministers will then issue a response, which we hope will lead to national roll out by April 2015.

Whilst screening for inclusion in the study has now finished, screening is ongoing at the study sites until 31 August 2014, by which time a decision on national policy will have been made. We've updated the information leaflet for Parents and Health Professionals, and request that midwives and health visitors distribute the updated version (v20) leaflet to new parents as soon stocks are received. Please destroy stocks of older leaflets.

If you have any queries about this please contact jason.sowter@sch.nhs.uk or your regional co-ordinator.

Expanded Newborn Screening

Advice for parents and health professionals



National Institute for
Health Research



www.expandedscreening.org



National Institute for
Health Research

Which activities are currently underway?

PHG Foundation

The PHG Foundation have completed their updated systematic review into the birth prevalence of our five disorders. They've revised their estimates of how prevalent the conditions are in Western populations. Some are now thought to be more common, and some less so, but the overall estimated prevalence of the five conditions is still almost the same; it is now 1:27,000 rather than 1:28,000.

Health Economic evaluation

Reports so far indicate that screening for all five conditions is cost saving. This information was provided to the National Screening Committee for their consideration.

Communication study

Louise Moody and her team at Coventry University are running the Communication Study, which will help to understand the most effective way in which information can be given and parents can be supported. Louise and her team have begun to contact the clinical leads at some sites, and letters have gone out to parents of screen positives through those sites. Site R&D approvals are currently being sought at other sites.

Films

Optical Jukebox have completed filming of six new films, and are now editing these. We hope to see finished versions of these films in March. Many thanks to all our volunteers!

Screening results update

We now have screening data for 18 months since we began the ENBS project. In that time only 243 parents have declined screening (0.04% of parents), and we have identified 21 true positives, and 28 false positives:

	MSUD	HCU	IVA	GA1	LCHADD	Total
True positives	2	2	6	8	3	21
False positives	1	1	23	1	2	28

As screening is now extended until 31 August 2014 we anticipate approximately 13 further true positive results. By that date we will have screened approximately 930,000 children.

Contact details

Dr Kathy Jeays-Ward has taken over the role of Project Manager, and can be contacted by email (k.jeays-ward@sheffield.ac.uk) or phone (0779 3592622). Jason Sowter is available by email (jason.sowter@sch.nhs.uk) or phone (0114 226 7980)

This project is supported by the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care for South Yorkshire (NIHR CLAHRC SY). The views and opinions expressed are those of the authors, and not necessarily those of the NHS, the NIHR or the Department of Health. CLAHRC SY would also like to acknowledge the participation and resources of our partner organisations. Further details can be found at www.clahrc-sy.nihr.ac.uk.
© Copyright Sheffield Children's Foundation Trust
2014