



# Newborn Bloodspot Screening Wales

## Sgrinio Smotyn Gwaed Newydd-anedig Cymru

Issue no.18 : February 2019

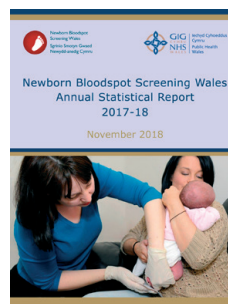
**Welcome to the eighteenth edition of the Newborn Bloodspot Screening Wales (NBSW) bulletin from the Screening Division of Public Health Wales. This bulletin will provide information and updates on the Newborn Bloodspot Screening Wales Programme.**

### The Second Newborn Bloodspot Screening Wales Annual Report shows more than 99% uptake

The second annual statistical report from NBSW was published in November 2018. It showed that 99.3% of newborn babies in Wales were tested for a number of serious but rare conditions in 2017/18.

The screening programme, managed by the Screening Division of Public Health Wales, offers eligible babies a test for the following conditions as recommended by the UK National Screening Committee:

- Congenital hypothyroidism (CHT)
- Cystic fibrosis (CF)
- Inherited metabolic disorders:
  - Medium-chain acyl-CoA dehydrogenase deficiency (MCADD)
  - Phenylketonuria (PKU)
  - Maple syrup urine disease (MSUD)
  - Isovaleric acidemia (IVA)
  - Glutaric aciduria type I (GA1)
  - Homocystinuria (HCU)
- Sickle cell disorders (SCD)



In the period covered by this report, 1 April 2017 to 31 March 2018, 31,932 babies were tested. The programme identified 39 babies with serious conditions.

#### Headline Statistics

##### April 2017 to March 2018

- The number of eligible births across Wales was 32,159
- The number of these babies tested was 31,932 (99.3%)

##### Completeness of offer and coverage (eligible newborns)

- Completeness of offer – 96.5% of babies had a bloodspot card (for screening or decline) received in the laboratory by day 14 of life (*standard 99%*)
- Coverage – 93.8% of babies had conclusive bloodspot screening results by day 17 of life (*standard 95%*)

##### Timeliness of sample collection

- Timely collection of sample (day 5-8 of life) – 97.9% (*standard 95%*)
- Timely collection of sample (day 5 of life) – 78.4% (*standard 90%*)

##### Avoidable repeat rate

- Avoidable repeat rate – 4.7% (*standard ≤ 2%*)

Improving performance in collecting good quality samples remains a high priority for the programme to avoid delays in the referral of babies.

##### NHS number on bloodspot card

- 99.1% of bloodspot cards received in the laboratory had a valid NHS number for the baby recorded (*standard 100%*)

##### Timely receipt of card in laboratory

- 93.9% of bloodspot cards were received within 4 working days of sample collection (*standard 99%*)

A copy of the report can be downloaded from: <http://www.wales.nhs.uk/sitesplus/888/news/49906>  
<http://www.wales.nhs.uk/sitesplus/888/newyddion/49907>

**Results letters will be sent for babies with a date of birth on or after 1st February 2019.**

For babies who have a suspected result for any of the conditions, the result letter will be sent via the baby's health visitor who will firstly be contacted by the programme.

Letters will also be sent to parents in situations where babies have not been screened or when screening has been declined. A 'not screened' letter will be sent to parents of babies who have not been screened despite attempts to offer and arrange sample collection. The letter recommends screening and provides information about what to do if they want their baby screened.

If parents decline all bloodspot screening tests, a letter confirming this will be sent together with the results explanation leaflet. The leaflet explains what the parents need to do if they change their mind and want to have their baby screened in the future.

All letters will be sent out by the three Regional Newborn Screening Administration Failsafe Teams and will replace the results reports that are currently sent from the Newborn Screening Laboratory to the Child Health Departments. Arrangements have been made for the Child Health Departments in Wales to access the results electronically.

We would like to thank everyone who has contributed to the development of this new process.

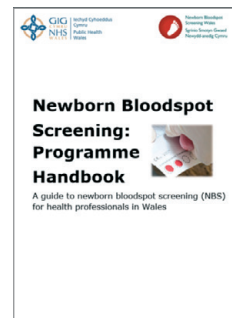
Please contact us via [NBSW@wales.nhs.uk](mailto:NBSW@wales.nhs.uk) if you have any queries or would like further information.

## New handbook published for health professionals

NBSW is pleased to announce the publication of a new handbook for health professionals in Wales.

The [NBSW Programme Handbook](#) informs and supports midwives, health visitors, neonatal nurses and other health professionals and staff who are involved in newborn bloodspot screening in Wales. It brings everything together in one place and can be used as a quick reference guide to answer specific questions about the programme. The guidelines for newborn bloodspot screening are included, with a separate section specifically for sample takers working in the neonatal units.

The handbook is now accessible on the [NBSW website](#) and has been developed with links throughout the document to allow easier access to further information. Guidance for accessing information in the handbook can be found on the second page.

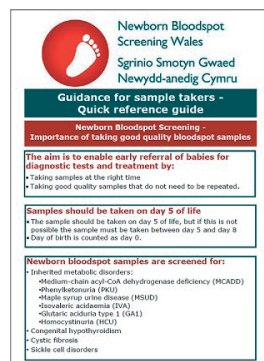


The handbook replaces the NBSW Health Professional information pack (A5 folder). Please could any copies of the information pack be discarded/destroyed as the information will no longer be current.

We hope that the handbook is useful and meets your needs. We welcome feedback and so please let us know via [NBSW@wales.nhs.uk](mailto:NBSW@wales.nhs.uk) if you have any comments or questions.

We would like to thank the NHS Newborn Blood Spot Screening Programme in England for kindly agreeing for us to adapt their handbook for use in Wales.

## Quick reference guidance for sample takers updated



The guidance for sample takers that was previously included in the NBSW Health Professional Information Pack has been updated and will be available separately on our website. Feedback from the health boards was that this guidance, renamed [Guidance for sample takers – Quick reference guide](#) will be useful for students and new sample takers.

The guidance, which is A5 size when printed and folded, can also be accessed via a link in the new handbook.

## New guidance developed for paediatric units

Newborn bloodspot screening samples are only occasionally taken on paediatric wards and units. In view of this, a quick reference guide has been produced for paediatric staff so they know what is required to take a good quality sample.

The guidance which can be displayed as a poster, is currently being distributed by the governance leads in each health board. It can also be accessed via the [NBSW website](#).



## New training film for sample takers in neonatal units

NBSW has produced a short film for sample takers working in neonatal units. It looks at aspects of newborn bloodspot screening for babies who are being cared for in neonatal units, and the additional requirements needed for screening these babies. This is available on the NBSW website.

We would like to thank all the parents and staff who were involved in the production of this film.

[Newborn bloodspot screening in neonatal units](#)

## Letters thanking sample takers will be sent after a condition is confirmed

When a baby is identified as having a condition following newborn bloodspot screening, the programme will send the sample taker a letter to thank them for taking the sample. These letters will be sent to sample takers after babies with dates of birth from 1.2.19 are diagnosed with a condition.

The only information stated in the letter will be the date of the sample, the name of the condition and the age of the baby when they were received into clinical care. It will not include any of the baby's personal identifiable information.

This letter has been produced in response to sample takers who said it would be of value to them to know that their part in the screening process has led to the identification and subsequent treatment of a baby with a condition.

## Sample Taker Database work continues

NBSW is continuing the work to establish a database of all sample takers in Wales. This is in preparation for sample taker performance reporting, and will enable the programme to communicate with sample takers and to update them of any changes.

In the future, it is planned that reports will be sent out to the health boards providing bloodspot screening performance data for the health board and a report on individual sample taker performance. It is planned that sample takers will also receive reports detailing their own performance which, in other screening programmes where this is done, is positively received by sample takers.

For this to work, all sample takers will need to be registered on the NBSW System. The governance leads are working with us to identify those who have not yet registered.

The sample taker name and ID (NMC number or ID number issued by NBSW for those without an NMC number) must be legibly recorded on the bloodspot card so that it can be entered on to the Laboratory IT system. The use of stamps to record the sample taker name and ID are used by some staff and this has been welcomed by the laboratory.

To register, sample takers are being asked to complete the NBSW sample taker registration form and return it to us via [nbsw@wales.nhs.uk](mailto:nbsw@wales.nhs.uk) or to send it to us at: **Newborn Bloodspot Screening Wales, Floor 4, Number 2 Capital Quarter, Tyndall Street, Cardiff, CF10 4BZ.**

The sample taker registration form can be found on our website. If you have any questions about registration please contact us.

## NBSW welcomes a new programme coordinator

NBSW welcomes Margaret Birch into her new role of Programme Coordinator which starts this month. Before joining NBSW, Margaret was the antenatal and newborn screening governance lead in the Abertawe Bro Morgannwg University Health Board.

Margaret is replacing Chris Bovington who is now working as a Regional Coordinator in the Antenatal Screening Wales Programme. We wish them both all the best in their new roles.

The NBSW Programme Coordinators can be contacted if there are any questions about newborn bloodspot screening. Their contact details are below.



## Contact numbers for the Newborn Screening Administration Failsafe Teams

Cardiff and Vale, Cwm Taf and Aneurin Bevan University Health Boards: Tel – 029 2074 3568

Abertawe Bro Morgannwg and Hywel Dda University Health Boards and Powys Teaching Health Board: Tel – 01656 754085

Betsi Cadwaladr University Health Board: Tel – 01978 727005

## Contact numbers for the Wales Newborn Screening Laboratory

Health professionals should use the following telephone numbers to contact the laboratory:

**1. To check that a sample has been received, or for any queries about demographic information on a bloodspot card:**

Telephone – 029 2074 4032

Laboratory Fax number – 029 2074 4065

**2. For all clinical enquiries (including interpretation of screening results) please contact:**

Dr Fiona Stratford, Clinical Biochemist: Telephone – 029 2074 5448

Email: [Fiona.stratford@wales.nhs.uk](mailto:Fiona.stratford@wales.nhs.uk)

Professor Stuart Moat (Consultant Clinical Biochemist), Director of Wales Newborn Screening Laboratory: Telephone – 029 2074 3562

Email: [stuart.moat@wales.nhs.uk](mailto:stuart.moat@wales.nhs.uk)

## Contact numbers for the NBSW Programme

The address and telephone numbers for the NBSW Head of Programme, Co-ordinators and Administration Support Team are:

Ruth Lawler, Head of Maternal and Child Screening: Telephone – 029 2010 4432

Email: [ruth.lawler@wales.nhs.uk](mailto:ruth.lawler@wales.nhs.uk)

Catherine Boyce, NBSW Programme Co-ordinator: Telephone 029 2010 4399

Email: [catherine.boyce2@wales.nhs.uk](mailto:catherine.boyce2@wales.nhs.uk)

Margaret Birch, NBSW Programme Co-ordinator: Telephone 029 2010 4634

Email: [margaret.birch@wales.nhs.uk](mailto:margaret.birch@wales.nhs.uk)

Administration Support Team: Telephone 029 2010 4427

Email: [nbsw@wales.nhs.uk](mailto:nbsw@wales.nhs.uk)

Address: Newborn Bloodspot Screening Wales, Floor 4, Number 2 Capital Quarter, Tyndall Street, Cardiff, CF10 4BZ

**Contact Us:** If you have any queries or questions about the Newborn Bloodspot Screening Wales programme, or would like to be added to our circulation list, please contact us at [nbsw@wales.nhs.uk](mailto:nbsw@wales.nhs.uk)



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