

NHS Sickle Cell and Thalassaemia Programme News

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sct.screening.nhs.uk

October 2014

Newborn outcomes project

The Newborn Outcomes Project has nearly completed its fourth consecutive year and is making good progress. Our success has been attributed to the continued support from the newborn screening laboratories, the specialist centres and hospital clinics for providing us with the data.

The Sickle Cell Society and the UK Thalassaemia Society are on the governance group and have worked with us to ensure the project meets the needs of service users. Thank you all for your help and support.

The main aims of the project are to establish whether babies are seen by a clinician and prescribed the prophylaxis treatment by three months of age and to review the mother's antenatal screening.

As of July 2014, we have been notified of 1,282 screen positive babies, 67% with confirmed sickle cell disease and just over 5% with beta thalassaemia. Preliminary analysis suggests that 72% of all affected babies were followed up by a clinician and given the standard treatment. Antenatal results for the mother were available for 77% of cases.

For more information please see: sct.screening.nhs.uk/evaluation

Excellent Review for King's College SCT Courses



Training for clinicians

This year, the SCT programme offered a number of courses for clinicians taught by King's College London.

One course is for staff delivering counselling to 'at risk' couples and occurred in May and June this year. Altogether there were 38 participants, 25 of them receiving bursaries from the SCT programme. One attendee's comment, "The course has really elevated my knowledge of genetic counselling, genetic inheritance, and issues related at risk couples" reflects the experience of most other participants. Over 90% said that it greatly increased their knowledge of

the subject.

Study days for non-specialists (nurses, midwives, health visitors and others) also taught by King's College London were held in London in April 2013 and Manchester in July 2014. Twenty-two people attended the London course and 38 in Manchester. One person's comment that, "I have been on a number of screening/NBSS study days. Today's presentation surpassed of all of those and my knowledge has greatly improved", reflected many others as over 80% said that the course greatly reinforced/increased their skills and knowledge.

Resource for teachers

In a first for the NHS, the SCT screening programme has produced a set of resources for GCSE science teachers to use when teaching genetic inheritance.

The free resource has been created to support the teaching of GCSE science and uses sickle cell and thalassaemia as models to demonstrate how serious conditions can be inherited.

Cathy Coppinger, NHS Sickle Cell and Thalassaemia Screening Programme Manager, said:

"Genetic inheritance is part of the GCSE science curriculum and we know sickle cell disease is often used as an example of how it works. We wanted to help teachers by providing them with resources that bring these issues to life."

"It is likely that students will go on to have to make decisions about sickle cell and thalassaemia tests and screening, so resources like this are important for building 'genetic literacy'."

"There is still a lack of public understanding around sickle cell and thalassaemia and there remains stigma which can be a barrier to accessing both health services and screening."



Outreach project update

The SCT screening programme has been running community outreach programmes since 2005. These programmes aim to raise awareness in the community on sickle cell disease and thalassaemia, their mode of inheritance, available screening and diagnostic testing, clinical care pathways and lifelong treatment and management.

The SCT screening programme is currently producing an online outreach resource tool as good practice guidance for health programmes. This will help health professionals, commissioners and the voluntary sector to develop, implement and evaluate an outreach programme addressing health issues.

The resource includes a case study about the work undertaken by the screening programme. It also includes learning from other successful outreach projects in health. The SCT screening programme is planning to launch the resource tool by October/November 2014.

The family legacy film

Since 2009, the Sickle Cell Society has conducted the SCT screening programme's outreach to raise awareness of sickle cell disease, testing and associated myths, particularly among high risk African and Caribbean communities.

'The Family Legacy', a film about the impact of sickle cell disease on a marriage and a family, is screened in churches, colleges, family homes, barbershops, television etc. reaching thousands of people nationally and internationally. On Sunday, 23 February 2014 a facilitated session billed 'Sickle Cell Disease: The Family Legacy and Africanus Horton Story'



Iyamide Thomas gives presentation on Dr Africanus Horton



Scene is set for Maroons restaurant Screening

was held at 'The Maroons' Caribbean restaurant.

It innovatively and successfully combined sickle cell awareness and a heritage presentation on Dr Africanus Horton, credited for being the first written description in 1874 of the disease that subsequently became known as sickle cell.

Iyamide Thomas, Regional Care Advisor, Sickle Cell Society

Find out more

Video footage from the session can be viewed at:

vimeo.com/88504854

The film can be viewed at:

www.familylegacy.org.uk

Learning from incidents

The UK NSC promotes a culture of raising and investigating problems in order to improve screening programmes. This vignette shows how one trust responded to an incident.

What happened?

The baby was identified as a sickle cell disease carrier by newborn blood spot screening. This was not expected. Look back at the antenatal screening

history of the family showed that the Family Origin Questionnaire (FOQ) had not been used appropriately.

What should have happened?

You need to ask for the family origins of both the woman AND the baby's father going back at least two generations (or more if possible). Notes on this are on

the back of the Family Origin Questionnaire (FOQ). [More info](#) is on the website.

Learning points

Since this happened, training in the Trusts has emphasized the need to ask for the family origins of both the woman AND the baby's father going back at least two generations (or more if possible).

UKTS pushes awareness

2014 is turning out to be a bumper year for thalassaemia awareness! The UK Thalassaemia Society has been working harder than ever this summer, with record attendance at melas and festivals all over the country.

We have distributed thousands of leaflets, books and films to members of the public; and of course spoken to many hundreds of festival goers about thalassaemia, its inheritance pattern and the fact that a test for the carrier state is available before having a family. We are already planning our awareness work for 2015 and hope to double the number of festivals we attend next year.

We are also continuing with our "UKTS Roadshow" project and have so far held Roadshow events at the Carlisle Business Centre in Bradford on 31 May and the MAC Centre in Birmingham on 16 August.

UKTS has taken awareness stalls at the following community events in 2014:

- Vaisakhi Festival, Slough 27 April
- Middlesbrough Mela, 7 & 8 June
- Bradford Festival, 13, 14 & 15 June
- Manchester Mega Mela, 21 & 22 June
- Sandwell & Birmingham Mela, 5 & 6 July
- Slough Mela, Upton Park, Slough 3 August
- Birmingham Eid Mela, Cannon Hill Park, Birmingham 17 August
- Leicester Belgrave Mela, Leicester City Centre, 25 August
- London Mela, Gunnersbury Park, Ealing, 31 August



UKTS Vice-President Anand Singh Ghattaura with our stand at the Sandwell & Birmingham Mela, Victoria Park, Smethwick

Laboratory Accreditation

New quality assurance (QA) processes for the national antenatal and newborn screening programmes are now being implemented, led by the *regional QA teams*.

The screening programmes and UK Accreditation Service (UKAS) have been working together to incorporate the assessment of the national screening standards for antenatal and newborn screening into the UKAS accreditation process. This has resulted in an agreement between the two organisations so that when a laboratory which participates in a national screening programme for antenatal and newborn screening is assessed by UKAS to ISO 15189, the assessors will also include conformity with national screening standards.

To help the laboratories prepare for the UKAS assessment, the screening standards have been assembled into a *table and mapped against the UKAS standards*. The first UKAS visits incorporating an assessment of the antenatal and newborn screening programmes are expected in October 2014.

Earlier screening recommended

Following the UK National Screening Committee [meeting on 18 June](#), the UK NSC has recommended earlier screening for [Edward's Syndrome \(T18\)](#) and [Patau's Syndrome \(T13\)](#) in pregnancy.

The Committee recommended against screening for atrial fibrillation, type 2 diabetes and parvovirus.

Current policy consultations:

- [Dementia](#) (closes 9 October)

- [Preterm birth](#) (closes 17 October)
- [Bacterial vaginosis](#) (closes 17 October)
- [Gauchers disease](#) (closes on 6 November)
- [Depression](#) (closes 26 December)

Consultations due to start soon:

- [Amino acid metabolism disorders](#)
- [Sudden cardiac death](#)
- [Galactosaemia](#)
- [Fatty-acid oxidation disorders](#)



UK National
Screening Committee

Transition begins

The transition of the NHS screening website content to NHS Choices and GOV.UK has begun.

Online information for the public is going to NHS Choices and information for professionals is moving to GOV.UK. The e-learning screening modules will also be moving to a new home in due course.

The process is due to be completed by January 2015 and should increase the number of visitors to our websites, provide a more integrated approach to providing information across all NHS screening programmes – cancer and non-cancer – and allow better integration of information with other parts of Government and the NHS.

The first stage in the process saw public content on abdominal aortic

New screening content set up on NHS Choices

aneurysm (AAA) screening go live on NHS Choices in [November](#). The existing [aaa.screening.nhs.uk](#) site will remain operational until the migration of all AAA screening content is complete.

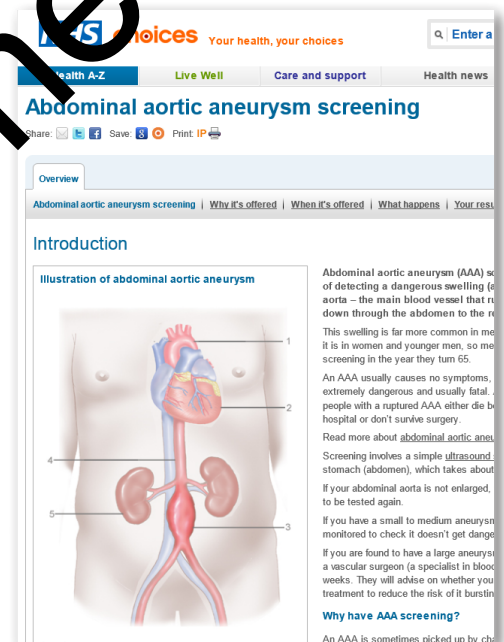
Diabetic eye screening content will be the next to go live.

Follow us on Twitter



The Twitter account, [@PHE_Screening](#), is a great source of information on health

screening in England. Please feel free to follow and engage with the account.



The new abdominal aortic aneurysm screening information for the public on the NHS Choices website

Other news in brief

Antenatal and newborn e-learning module

The UK NSC's popular *antenatal and newborn screening e-learning module* has recently been updated, including new questions in the quiz.

Education Resource for PICU/ NICU Practitioners

The UK NSC has just launched a *new*

educational resource for PICU/NICU practitioners, covering the three newborn screening programmes.

Screening induction resource

The *screening induction resource* has been re-designed, updated and improved. The resource is for use by local screening coordinators to facilitate induction sessions for new staff, provide information to health professionals or for refresher courses.

Screening in England 2012/13 report

The *Screening in England annual summary* for 2012-13 has now been published on the UK NSC website. The report covers the final year before the NHS Screening Programmes became part of Public Health England. The summary highlights the progress of the eight national non-cancer screening programmes throughout the year and outlines key successes using data and case studies.