The Royal College of Pathologists
Pathology: the science behind the cure

To screen or not to screen?

Objects in 'A History of Pathology in 50 Objects' this resource links to:

Neonatal blood spot card: *http://www.rcpath.org/the-college/50th-anniversary/50-objects/objects1_10/object-7-neonatal-blood-spot-card*

Learning Objectives

- Understanding of social, ethical, health and safety and moral implications
- Learning about inherited conditions
- Understanding the advantages and disadvantages of new developments
- Understanding health, diet, drugs and disease
- Exploring contemporary and historical scientific developments and how they have been communicated
- Learning to question and discuss issues that may affect students own lives or have impact on the world and the directions of societies.

Materials required

- **Disease cards**
- **Slips of paper with inherited conditions or healthy babies**
- **Screening fact sheet**
- **Neonatal blood cards (or images of)**

Time taken: 15-20 minutes (per activity)

Picture link

Show the students a neonatal blood spot card (or a picture of one). Have any of them seen one before? Do they know what it is?

What are the advantages of testing dried blood drops on cards? Answer: ease of transport, easily stored, useful for further research.

Practical/Discussion activities

Give all students a copy of the screening factsheet, and go through some of the important points and facts: what screening is, what neonatal blood spot cards can screen for, how early treatment such as changing a diet can be life-saving etc.

'Parallel lives': You are parents

In this activity, students are soon-to-be parents. This activity will bring an understanding about lack of screening programmes in certain areas, as well as what life would have been like before screening programmes and the technology was available.

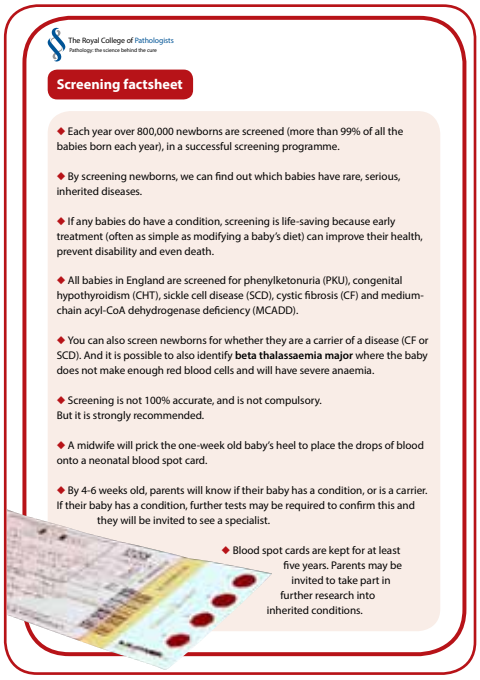
Split the class into two. One half (Parents A) live in a world where there is no neonatal screening. The other half (Parents B) live in a world with a very successful neonatal screening programme, where 99% of babies are screened for inherited diseases.

Print out enough slips of paper or card, which have the phrase **'Your newborn baby is healthy'**. You do not need too many of these, as the activity will take longer if you have too many. Also print out the five **'Your newborn baby has __ condition'**. Fold all these slips, and place them into a container for students to pick like in a 'lucky dip'.

Unless parents are aware that they are carriers of a disease, they will have no idea of any inherited conditions that their newborn child might have. (Hence the 'lucky dip' nature of this activity).

Ask a 'parent' from the **Parents A** group to come to the front of the classroom/lab and ask them to pick someone from **Parents B** group who will join them. One of them picks a slip of paper from the 'lucky dip' and reads the statement. If it says 'Your newborn baby is healthy' then both of them can sit down (relieved!). This means that wherever each parent was based, they have a healthy child.

If however they find out that their babies have a condition, give them the appropriate disease card and ask one of them to read it out.



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Screening factsheet

- Each year over 800,000 newborns are screened (more than 99% of all the babies born each year), in a successful screening programme.
- By screening newborns, we can find out which babies have rare, serious, inherited diseases.
- If any babies do have a condition, screening is life-saving because early treatment (often as simple as modifying a baby's diet) can improve their health, prevent disability and even death.
- All babies in England are screened for phenylketonuria (PKU), congenital hypothyroidism (CHT), sickle cell disease (SCD), cystic fibrosis (CF) and medium-chain acyl-CoA dehydrogenase deficiency (MCADD).
- You can also screen newborns for whether they are a carrier of a disease (CF or SCD). And it is possible to also identify **beta thalassaemia major** where the baby does not make enough red blood cells and will have severe anaemia.
- Screening is not 100% accurate, and is not compulsory. But it is strongly recommended.
- A midwife will prick the one-week old baby's heel to place the drops of blood onto a neonatal blood spot card.
- By 4-6 weeks old, parents will know if their baby has a condition, or is a carrier. If their baby has a condition, further tests may be required to confirm this and they will be invited to see a specialist.
- Blood spot cards are kept for at least five years. Parents may be invited to take part in further research into inherited conditions.

Ask the whole class:

What does this mean for Parent A?
What does this mean for Parent B?

Obviously Parent A will not have had their child screened, so would not know about the condition. What will happen to their child?

Parent B however can make lifestyle changes to have a child that will live healthier and longer, because screening means early treatment.

Alternate between Parent groups as to who picks whom to come to the front with them, and who picks in the 'lucky dip'.

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Your newborn baby is healthy	Your newborn baby is healthy	Your newborn baby is healthy
Your newborn baby is healthy	Your newborn baby is healthy	Your newborn baby is healthy
Your newborn baby is healthy	Your newborn baby is healthy	Your newborn baby is healthy
Your newborn baby is healthy	Your newborn baby is healthy	Your newborn baby is healthy
Your newborn baby is healthy	Your newborn baby is healthy	Your newborn baby is healthy
Your newborn baby has Phenylketonuria (PKU)	Your newborn baby is healthy	Your newborn baby is healthy
Your newborn baby has Sickle cell disease (SCD)	Your newborn baby is healthy	Your newborn baby is healthy
Your newborn baby has Congenital hypothyroidism (CHT)	Your newborn baby is healthy	Your newborn baby is healthy
Your newborn baby has Cystic fibrosis (CF)	Your newborn baby is healthy	Your newborn baby is healthy
Your newborn baby has Medium-chain acyl-CoA dehydrogenase deficiency (MCADD)	Your newborn baby is healthy	Your newborn baby is healthy

‘The tables have turned’: You are pathologists

In this activity all students are pathologists, and can be in groups or discuss as a class. They will have access to the Screening Factsheet and all information about the diseases. They are presented with the following scenario (which can be projected on a slide):

A couple who have just had a newborn child are worried about their child being screened. How would you convince them that screening is important?

In the UK parents rarely oppose testing, however parents may want to know more when they are asked to give consent for testing. How would you discuss the parents’ concerns, if you were faced with the following questions:

- Why do we need to bother with screening?
- Why do you need to keep my child’s blood spot records on file?
- What if I find out my child is a carrier for a disease? I would rather not know!
- What if my child has a disease, I don’t think I will be able to cope? Is it going to cost me a lot in treatments?

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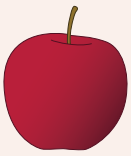
Disease Cards

Phenylketonuria (PKU)

How many are affected?
1 in 10,000 babies born in the UK has phenylketonuria (PKU).

What is it?
Babies with this inherited condition cannot process the amino acid, phenylalanine, in their food. If untreated, they will develop irreversible mental disabilities.

How can screening help?
Screening means that babies with the condition can be treated with a special low protein, high fruit and fibre diet. It is often too late to give a special diet and make a difference to an unscreened baby found to have PKU later in life. This early treatment can prevent serious illness and allow babies to live longer, healthier lives.



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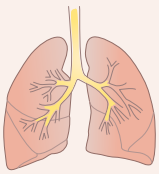
Disease Cards

Cystic fibrosis (CF)

How many are affected?
1 in 2,500 babies born in the UK has cystic fibrosis (CF).

What is it?
Babies with this inherited condition produce excess sticky mucous which affects the lungs and digestive tract. Babies with CF may not gain weight, have regular chest infections, shortness of breath and coughing.

How can screening help?
Screening means that babies with the condition can be treated with a high-energy diet, medicines and physiotherapy. This early treatment can prevent serious illness and allow babies to live longer, healthier lives.



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Disease Cards

Congenital hypothyroidism (CHT)

How many are affected?
1 in 4,000 babies born in the UK has congenital hypothyroidism (CHT).

What is it?
Babies with this inherited condition do not have enough of the hormone thyroxine, because of an underactive thyroid gland. This hormone is needed for growth, and as a result babies with CHT do not grow properly and can develop physical and mental disabilities.

How can screening help?
Screening means that babies with the condition can be treated with thyroxine tablets to prevent serious disability. It is often too late to give thyroxine and prevent disability in an unscreened baby found to have CHT later in life. This early treatment can prevent serious illness and allow babies to live longer, healthier lives.

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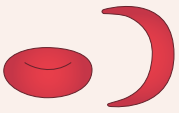
Disease Cards

Sickle cell disease (SCD)

How many are affected?
1 in 1,900 babies born in the UK has sickle cell disease (SCD) or sickle cell anaemia.

What is it?
Babies with this inherited condition have sickle-shaped red blood cells, which can block small blood vessels. This causes pain, serious infections, and even death.

How can screening help?
Screening means that babies with the condition can receive immunisations and antibiotics. This early treatment can prevent serious illness and allow babies to live longer, healthier lives. illness and allow babies to live longer, healthier lives.



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Disease Cards

Medium-chain acyl-CoA dehydrogenase deficiency (MCADD)

How many are affected?
1 in 10,000 babies born in the UK has MCADD.

What is it?
Babies with this inherited condition cannot break down fats to make energy for the body. They can become seriously ill, or even die.

How can screening help?
Screening means that babies with the condition can be recognised early, their diet can be modified to contain high energy foods and parents can make sure they are eating regularly. This early treatment can prevent serious illness and allow babies to live longer, healthier lives.

Useful links

Newborn Screening Programme Centre: *http://newbornbloodspot.screening.nhs.uk/public*

Angelina Jolie’s double mastectomy: *www.nytimes.com/2013/05/14/opinion/my-medical-choice.html?smid=tw-share&_r=1&”* - if you could screen a baby for the BRCA1 and BRCA2 genes (linked to an increased risk of breast and ovarian cancer), would you?