TEACHER'S NOTES

TO SCREEN OR NOT TO SCREEN

OVERVIEW

Aimed at key stage 4 pupils.

This activity involves a discussion around the ethics of screening programmes for Duchenne Muscular Dystrophy (DMD).

CURRICULUM LINKS

- **KS4**: Human health is affected by a range of environmental and inherited factors, by the use and misuse of drugs and by medical treatments
- **KS4**: The use of contemporary scientific and technological developments and their benefits, drawbacks and risks
- **KS4**: How and why decisions about science and technology are made, including those that raise ethical issues and about the social, economic and environmental effects of such decisions

LEARNING OBJECTIVES

- To consider the complex issues surrounding screening programmes for genetic conditions

PREPARATION

- Print worksheets
- Make large **AGREE** and **DISAGREE** labels for the classroom walls

Activity

- Watch **Connor's film** on the Genes Are Us website
- Divide the students into small groups and ask them to discuss the 3 scenarios
- Ask the groups to discuss their reactions to these statements for 5-10 minutes and ask them to decide how strongly they agree or disagree with them.
- Put a label at the front wall of the classroom saying **AGREE** and a label saying **DISAGREE** at the rear wall and ask the pupils to stand somewhere on that continuum (depending on how strongly they feel – those feeling strongest stood by the wall)
- Invite the pupils to share their point of view.
- You could introduce new points to consider (see suggestions below) to add to the discussion. You could ask if they want to revise their position on the continuum after hearing from other people.

WARNING: this could be a highly sensitive issue, so be aware that some pupils might know boys affected by this condition or these discussions might touch upon strongly held beliefs.

Emphasise that we're all entitled to different opinions and need to be respectful of different perspectives. It helps to generate discussion if you ask the class open questions and remain neutral, rather than reveal your personal opinion.

Suggested points to raise with the students during the discussion:

Discussion 1:

- What are benefits of a family knowing early? One answer - it could prevent a second child with the condition being born in the same family, and may also have an impact on the wider family (e.g. siblings of parents may then decide to be tested before having children).

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Activity continued

- Could it affect the way a mother interacts with her baby if she knows they will become ill?
- The majority of parents of boys diagnosed with DMD following screening in Wales are in favour of screening, saying that it gives them time to come to terms with the diagnosis and reproductive choice.
- This condition affects one in 3500 boys, is it a waste of money to offer screening to everyone? Would the money be better spent on researching treatments such as gene therapy?

Discussion 2:

- Current criteria for screening programmes in the UK require that a treatment is available, which it is not for DMD.
- Could a 15-year-old cope with this information? Would it be better to wait until they are 18? Would this information affect their future relationships?
- Should the test be compulsory? If not, how may someone feel if they declined the test then gave birth to a child with DMD?

Discussion 3:

- Is it ethical to discard affected embryos? The PGD technique used is currently licensed for 50 genetic conditions, including DMD.
- Should mothers be allowed to screen against female carriers of DMD as well as affected males?
- Will more choice about embryo selection lead to future discrimination of people with genetic conditions?
- Is it better to screen the embryos outside the body, rather than when the pregnancy is underway (the earliest a pre-natal test could be done is about 10 weeks into a pregnancy)

EXTENSION

A new test has recently been in the news that can screen parents before they have children for over 100 gene variants. The hope is that this will dramatically reduce the chances of having a child affected by a genetic condition. This test is available online and through the Bridge Fertility Clinic and it's called the Counsyl test. For more information about this news story, see: **www.bionews.org.uk/page_54404.asp**

You could ask pupils to write an article summarising the pros and cons of using this test.

FURTHER information

Newborn screening for Duchenne Muscular Dystrophy is not currently offered in England, but it is currently available in Wales. Around half of those who test positive initially are found not to have DMD when followed up. Research has been done and there is no evidence to suggest that this has any impact on the mother-baby relationship in this group.

Some countries have set up screening programmes with teenagers in schools eg. for cystic fibrosis and thalassaemia to identify carriers.

Embryo screening involved a technique called **Pre-implantation Genetic Diagnosis** (PGD). This involves a couple going through IVF and then the embryo develops for a few days before a single cell is removed and tested. The healthy embryos are then implanted in the mother and the affected embryos are usually then discarded.

See Genes Are Us Teacher Factsheet on DMD for basic information. For more detailed information, link to the patient support group: Muscular Dystrophy Campaign: **www.muscular-dystrophy.org**

PUPIL WORKSHEET

TO SCREEN OR NOT TO SCREEN

You are going to be asked to consider some challenging issues.

There are no right answers to these questions, so your judgement will depend on the information you know and the values you believe to be important.

DUCHENNE MUSCULAR DYSTROPHY

Information about **Duchenne Muscular Dystrophy (DMD)**

- DMD is a genetic condition which causes progressive muscle-wasting.
- It usually only affects boys. Girls can be carriers and in this condition this means that they could have subtle signs of the condition but won't develop the full-blown disorder.
- Babies appear normal at birth, however by the age of 8-11 affected boys can no longer walk and by their late teens or 20s the condition is severe enough to be life threatening.
- Around 100 boys with DMD are born in the UK each year.
- There's no cure, but many scientists are cautiously optimistic that one could become available in the near future.

Discuss the following statements around screening for DMD in a small group. Try to think about moral and ethical issues, as well as how these options might affect the families involved.

Decide where to place these statements on the 'agree – disagree continuum'.

All parents of baby boys should be offered a genetic test to find out whether their baby will develop DMD in the future.

All 15 year old girls should be offered a genetic test to find out whether they are carriers of DMD. This would identify those who could go on to have a baby boy with DMD.

Women who know they are carriers of DMD should be able to use embryo screening to make sure that they have a baby who is not affected by DMD. This could involve some embryos being discarded.