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Genetic Disorders UK

TEACHER'S NOTES

WOULD YOU WANT TO KNOW?

OVERVIEW

Aimed at **key stage 4** pupils. This worksheet explains that it is possible to predict whether someone will develop Huntington's disease (HD) in the future and encourages pupils to think about the pros and cons of finding out.

LEARNING OBJECTIVES

- To understand that it is possible to find out if an individual will develop HD in the future
- To understand that people at risk of HD have a number of factors to consider before deciding whether or not to take such as test

CURRICULUM LINKS

- KS4:** The ways in which organisms function are related to the genes in their cells
- 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:** to consider 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

Activity

- Discuss with the class how HD is inherited, its symptoms and its cause
- Watch the film Luke's story on www.genesareus.org
- Ask pupils to complete questions 1-5 independently
- Divide the class into small groups (with 3-5 pupils) to enable them to discuss the four statements near the end of the worksheet. Some groups might complete this quickly and need prompting to think more broadly.
- It might be helpful to ask questions such as:
 - is it the parent's right to decide on behalf of their child about DNA testing?
 - what difference does age make? The UK guidelines advise that predictive genetic testing for HD is only available to people aged 18 years+
- Open up the discussion to the whole class
- Ask pupils to complete question 6 on their own

ANSWERS

1. What are the main symptoms of Huntington's disease?

Huntington's disease affects the central nervous system. Symptoms include: difficulty controlling muscle movements, personality changes and problems with concentration, memory and communication. The symptoms get progressively worse over a number of years.

2. Which inheritance pattern explains the way HD is inherited?

b) dominant

3. Why do you think most people at risk do not want to have this predictive genetic test?

Pupils might mention many factors, such as implications on relationships and on their wider

family if they were to be told that they had inherited the genetic change that causes HD. They might say that people could feel depressed or hopeless about their future, if they received bad news. As there is no cure for HD, many people would prefer not to know and enjoy life without this knowledge about the future.

4. Imagine you had a parent with HD, would you want to find out if you were going to develop the condition? Explain your answer

Pupils are being asked a difficult question, but hopefully they give their answer careful consideration. Most people who are not at risk of HD answer 'yes' to this question. Most people who actually are at risk of HD answer 'no'. The table overleaf reflects some of the reasons that pupils might give.



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WOULD YOU WANT TO KNOW?

ANSWERS continued

YES – I'd want to be tested	NO – I wouldn't want to know
It would remove some of the uncertainty about my future health	It would be very hard to stay hopeful for the future if I knew I would get HD
I could arrange the right support and surveillance (that is, someone to watch for onset of symptoms) in the future	HD cannot be cured and there's nothing I could do to prevent the condition, so I'd rather not know
It would influence my life plans, such as whether to have children or not	I wouldn't want my life to be overshadowed by knowing this about my future health. It could change my life plans.
I would want to find out more about the best treatments and research into HD	It might cause financial problems with trouble getting insurance or a mortgage

5. Imagine your maternal grandfather had HD. Your mother is healthy, but has not had the predictive genetic test to find out whether she will develop HD in the future.

a) What is your risk of having inherited the changed version of the *htt* gene that causes HD?

25% (the mother is at 50% risk and her child's risk is half of that)

b) If you decide that you want the predictive genetic test for HD, how do you think your mother might feel about this and why?

Your results could have implications for your mother. If you were found to have the genetic change that causes HD, then she must have passed it onto you. She has decided that she doesn't want to know, so this situation would need resolving and hopefully a compromise could be reached. It would be very hard for anyone to find out the results of a predictive genetic test for HD and keep them secret.

FURTHER information

- The 'Citizen Science' website has resources to support teachers running discussion activities in the classroom and some of the resources explore genetic testing: www.at-bristol.org.uk/cz
- The BioEthics Education Project has some useful discussion activities, including ones focused on HD (follow 'Human Health' and then 'Genes & health'): www.beep.ac.uk

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WOULD YOU WANT TO KNOW

Huntington's disease (HD) is caused by a change in the *htt* (*huntingtin*) gene. In 1993 scientists pinpointed *htt*, and the genetic change that occurs in it to cause HD. By discovering the change it meant that it was possible to test individuals at risk of HD to find out if they would develop the condition in the future or not. This type of genetic test is quite unusual and is called a predictive genetic test.

When this predictive genetic test was first developed many people at risk of HD were interested in having it. In the past 20 years though, we have seen that the majority of people at risk decide that they do not want to have this DNA test.

It is important to remember that HD is an inherited condition and that people who have a parent with HD have a 50:50 chance of inheriting the condition themselves. The genetic change causing the condition is something that people are born with, so in theory the predictive test could be done at any age. If someone is born with the gene change in *htt*, we know that they will develop the condition in the future, but we cannot tell at what age. Because HD does not usually develop until mid life, typically after the age of 35, people who will go on to develop the condition still can lead full and happy lives.

- 1 **What are the main symptoms of Huntington's disease?**
- 2 **Which inheritance pattern explains the way HD is inherited?**
 - a) sex-linked
 - b) dominant
 - c) recessive
- 3 **Why do you think most people at risk do not want to have this predictive genetic test?**
- 4 **Imagine you had a parent with HD, would you want to find out if you were going to develop the condition?**

Explain your answer
- 5 **Imagine your maternal grandfather had HD. Your mother is healthy, but has not had the predictive genetic test to find out whether she will develop HD in the future.**
 - a) **What is your risk of having inherited the changed version of the *htt* gene that causes HD?**
 - b) **If you decide that you want the predictive genetic test for HD, how do you think your mother might feel about this and why?**

Discuss the four statements on the next page in groups. These are difficult scenarios and you need to make a judgement about them; there are no right or wrong answers. As a group, you need to decide whether you agree or disagree with each statement. You might have quite different reactions to the other people in your group, so it is important to listen carefully and try to explain clearly why you feel the way you do.



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WOULD YOU WANT TO KNOW

STATEMENT 1

A 15 year old wants to have a predictive test for HD, but his parents do NOT agree with his request. He should be allowed the test.

STATEMENT 2

An 11 year old wants to have a predictive test for HD and her parents agree with her request. She should be allowed the test.

STATEMENT 3

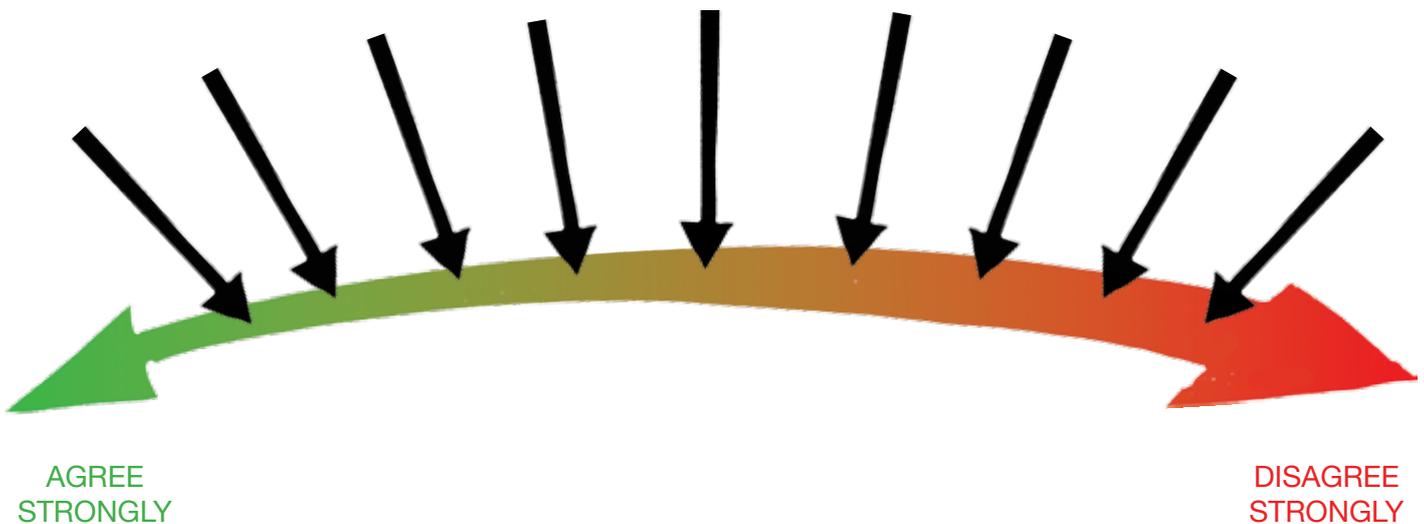
All parents of newborn babies should be offered the predictive test for HD.

STATEMENT 4

A 30 year old wants a predictive test for HD, but he is clinically depressed and professionals are concerned about how he'll cope with bad news. He should be allowed the test.

6

Copy the diagram below. Show how strongly you agreed or disagreed with the statements by writing the number of each statement next to an arrow in the diagram. Explain why you agreed or disagreed with each statement.



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