

UNIT 1: WHAT'S IT GOT TO DO WITH ME?

TEACHERS' NOTES - UNIT 1

WHAT'S IT GOT TO DO WITH ME?

OBJECTIVES

To encourage students to appreciate that genes affect us all. To learn more about how different recessively-inherited genetic conditions can affect people's lives.

SUGGESTED AGE RANGE 14-16 year olds.

CURRICULUM LINKS

For use in PSE, English, Drama, Social/Contemporary Studies and Science (National Curriculum Science (Double) at KS4, Life Processes and Living Things, Section 4: Variation, inheritance and evolution. 'Pupils should be taught... that some diseases can be inherited.1)

SUMMARY OF CONTENT

All students complete an Activity Sheet at the beginning of the lesson in order to focus attention on ways in which everyone is affected by genes. Four Case Studies encourage students to explore some of the human and social consequences of living with a genetic condition.

TEACHERS PLEASE NOTE

It is important to be aware of the fact that some students in the class may themselves have a genetic condition, or be a carrier, or have a relative who is affected. Sensitivity is required to avoid putting such students under stress.

You might like to read through the Notes for Teachers on the Activity Sheet/Case Studies on pages 4—6 before the lesson.

MATERIALS NEEDED

One copy per pair of students of Activity Sheet A – This activity sheet is all about... YOU!

Photocopies of whichever Case Studies you have selected for use with your students (there are four to choose from), plus the Genetic Condition Card which goes with each Case Study:

Case Study 1 (Khadija) plus Genetic Condition Card: Sickle Cell Anaemia.

Case Study 2 (Hifsa) plus Genetic Condition Card: Thalassaemia

Case Study 3 (Richard) plus Genetic Condition Card: Laurence-Moon-Bardet-Biedl Syndr. (LMBBS)

Case Study 4 (Chris) plus Genetic Condition Card: Glycogen Storage Disease.

(N.B. Case Study 2 is longer than the others and requires good reading skills. One Case Study and Genetic Condition Card per pair of students is required.)

WHAT YOU DO

Ask students to get into pairs. Give each pair a copy of Activity Sheet A and ask them to work through it together. When they have done so, ask someone to read out what they have written in answer to the question, 'What is the common link between these three things?' (The answer is that the shape of your earlobes, hairline and whether or not you can roll your tongue are all determined by genes.) Remind students that there are thousands of different conditions caused by genes and some of these will affect a person's health or quality of life, while others do not. (for example whether your earlobes are attached or unattached)

Explain that during this lesson, students are going to read in pairs about a person who is either personally affected in some way by a genetic condition, or who works with people who are affected. Then give each pair a copy of the Case Study you have selected for them plus a copy of the relevant Genetic Condition Card and set a time for them to read through both and answer the questions.

N.B. There are four Case Studies to choose from. Each Case Study explores different aspects of a different genetic condition and requires different skills and reading abilities. All four genetic conditions featured are recessively inherited, so if you are a science teacher, you might like to take a few minutes to remind students of the difference between dominant, recessive and X-linked patterns of inheritance. You can then: EITHER select one Case Study out of the four and have all pairs of students working on the same Case Study OR select more than one Case Study and have pairs of students working through different Case Studies. When students have completed the questions on their Case Study, you may like to process the activity using the Notes for Teachers on the Activity Sheet/Case Studies to help you.

TEACHERS' NOTES UNIT 1

NOTES ON ACTIVITY SHEET A

The purpose of Activity Sheet A is to draw students' attention to simple, concrete ways in which genes influence everyone's physical development. The common link between the three things on the sheet is that they are all determined by genes.

NOTES ON CASE STUDY 1 – KHADIJA

Please see the Genetic Condition Card: Sickle Cell Anaemia for more information about this condition. In her poem, Khadija paints a powerful but bleak picture of sickle cell anaemia. Her use of words such as 'malady' and 'plague' and the lines 'It sucks the blood to survive' and 'It eats away at the immunity that protects against other maladies' suggest some deep, sinister threat from within. There is, she says, 'no happy ending' because sickle cell 'kills its host'. But the poem ends with Khadija challenging the power of Sickle Cell — 'But soon I promise you, sickle malady, soon it will be your turn'.

Many people with Sickle Cell Anaemia are already challenging Khadija's view of the condition as a 'killer disease'. They are ordinary members of the community who live busy, successful and fulfilled lives. The fact that they also happen to have a genetic condition is of secondary importance.

The most important thing that a school (and individual students) can do is to be 'Sickle Cell aware'

Understand the difference between a person with Sickle Cell Anaemia and a person who is a carrier of the Sickle Cell trait (a person with the condition may or may not have bouts of ill-health associated with the condition; a carrier is not affected by the condition and may or may not be aware of her/his carrier status).

Offer emotional and practical support to young people with Sickle Cell Anaemia where and when appropriate. Avoid isolating or stigmatising them

Listen to what young people with Sickle Cell Anaemia say about their condition and take them seriously. Respond quickly to a young person having a Sickle Cell 'crisis' (who perhaps becomes suddenly unwell or complains of severe joint, abdominal or chest pains).

Be prepared to contact a parent/carer or the young person's doctor or hospital. Help a young person with Sickle Cell Anaemia to stay warm and dry. Strenuous outdoor games in cold or wet weather are to be avoided. Care should also be taken after swimming.

Do not allow a young person with Sickle Cell Anaemia to become dehydrated. This means allowing her/him to drink much more than normal and more often. Because of this, and because the kidneys may be affected, (s) he might need to go to the toilet more often.

Support a young person who has to take prescribed medication.

Know that some people with Sickle Cell Anaemia develop a yellowish tinge to the whites of their eyes and may be self-conscious about this. It can be mistaken for signs of an infectious disease, or lead to bullying.

Appreciate that Sickle Cell Anaemia may make a young person tired or lethargic. It can be difficult to concentrate if one is in pain.

Help a young person who misses lessons through ill health to keep up with her/his school/college work.

Anyone who is asked to take part in screening for carrier status should be given counselling before and after the test so that they understand what a positive or negative result might mean and can ask questions.

TEACHERS' NOTES UNIT 1

As Sickle Cell is more common in people of African or African-Caribbean descent, as well as people from India, Pakistan, the Middle East or the Eastern Mediterranean, you are more likely to be offered screening if you fall into any of these groups. If you find out that you are a carrier, you should be given information about your chances of having a child with Sickle Cell Anaemia. This might affect future reproductive decisions which you take. However some people worry that if they test positive for carrier status, they will be unfairly discriminated against when they apply for a job, insurance, mortgage etc

NOTES ON CASE STUDY 2-HIFSA

Please see the Genetic Condition Card: Thalassaemia for more information about this condition.

Part of Hifsa's job is to raise awareness of the fact that first cousins who marry are more likely to have a child with a genetic disorder than couples who are not related in any way (the reason for this is explained in her answer to the interviewer's question 'Why are first cousin marriages a problem?').

The choices which families might face after Hifsa has talked to them will vary.

Couples who are married and planning to have children might choose to go for genetic counselling to find out whether or not they are at risk of having a child with a specific genetic disorder such as Thalassaemia. They can then make reproductive choices based on this knowledge.

Couples who are married and expecting their first child might consider prenatal testing for specific genetic conditions (although the option of terminating an affected fetus is not acceptable to some people.)

It is important to stress, as Hifsa does, that genetic counselling is about giving people enough information for them to make their own choices and not about telling people how to live their lives.

Hifsa's job can involve passing on painful news to families. This news might be that someone in the family, perhaps a child, has a genetic condition which will need lifelong treatment or care. A genetic condition in the family has implications for other family members and relatives too. And in a community where first cousin marriages are common, people might not want to hear the message that the children of these marriages have a higher than average chance of being affected by a genetic condition.

Hifsa says that she enjoys being able to help families by listening to their concerns and by communicating with them in their own language. But she also says that she finds breaking bad news difficult because she knows that the families she talks to will understand what she is saying.

NOTES ON CASE STUDY 3 – RICHARD

Please see the Genetic Condition Card: Laurence-Moon-Bardet-Biedl Syndrome (LMBBS) for more information about this condition.

Parents who discover that their child has a genetic condition can experience many different emotions. These will of course vary according to the circumstances and will often change over time. Soon after the diagnosis of a genetic condition in the family, parents often feel guilty for passing on the faulty gene and some may feel sadness at the loss of some of the hopes and expectations they had for themselves and for their child. The fact that the condition is genetic also raises issues for parents who wish to have more children.

Deciding to have more children when there is a genetic condition in the family can be difficult particularly when, as with LMBBS, there is no clear test which will indicate whether or not the fetus is affected (in LMBBS, doctors use ultrasound scans to look for evidence of extra fingers and toes which is one possible indication of the condition.) For some genetic conditions, the fetus can be tested to see whether or not it is affected. If the test is positive, the parents must then decide whether to proceed with the pregnancy or to have a termination.

CROSS-CURRICULAR ACTIVITIES: UNIT 1 TEACHERS' NOTES

NOTES ON CASE STUDY 4 – CHRIS

Please see the Genetic Condition Card: Glycogen Storage Disease for more information about this condition.

Researching into a genetic disorder which affects either you or a member of your family could be very rewarding, particularly if you are part of a project which is trying to identify new treatments or improve the quality of life of people who have the condition. But it could also be difficult if progress is slow or if you discover something about the way the gene works or the long-term effects of the condition which you would rather not know.

Whether or not you would want to find out as much as you could about a condition might depend on a number of things e.g.

- the type of person you are
- your age
- your situation
- your current state of health
- how much information is available about the condition etc.
-

Most people with a genetic condition see themselves as people first. The fact that they have a genetic condition is just one aspect of their lives. They may decide to tell friends and people they trust. They may want lots of people to know because they want the public to have a better understanding of their condition. If their condition means that they have a physical or learning disability or special needs, they may not be able to choose who they tell.

Telling people can mean that a person gets emotional support and practical help if and when needed, but it sometimes also leads to employers, mortgage and insurance companies treating that person differently. Before telling a friend, ask yourself if you mind if this friend then tells someone else. Before passing on personal information about yourself in a formal setting, think about what will happen to this information. Can the person or organisation guarantee confidentiality?

ACTIVITY SHEET AND CASE STUDIES FOR STUDENTS UNIT 1

WHAT'S IT GOT TO DO WITH ME?

This activity sheet is all about you!



ANSWER THE FOLLOWING QUESTIONS WITH YOUR PARTNER:



A

1) Look at the line where your partner's hair grows above her/his forehead. Is this line straight as in picture A?



B

2) Or does it dip down into a V-shape (sometimes known as a 'widow's peak'.) in the middle as in picture B?

ACTIVITY SHEET AND CASE STUDIES FOR STUDENTS UNIT 1



3) Look at your partner's ears. Are his/her earlobes attached to the side of the head (as in picture C) or unattached (as in picture D)?



4) Above is a drawing of a person rolling her tongue lengthways into a U-shape. Ask your partner to try doing the same.

ACTIVITY SHEET AND CASE STUDIES FOR STUDENTS UNIT 1

PLEASE WRITE YOUR ANSWERS IN THE TABLE BELOW. ONE SIDE OF THE TABLE IS FOR YOU AND THE OTHER SIDE IS FOR YOUR PARTNER. PUT A CIRCLE ROUND THE ANSWER WHICH IS RIGHT FOR YOU:

My name is:		My partner's name is:	
1. I do/do not have: a straight hairline across my forehead.		1. I do/do not have: a straight hairline across my forehead.	
2. I have: attached/unattached earlobes.		2. I have: attached/unattached earlobes.	
3. I can/cannot: roll my tongue.		3. I can/cannot: roll my tongue	

Q. WHAT IS THE COMMON LINK BETWEEN THESE THREE THINGS?

ACTIVITY SHEET AND CASE STUDIES FOR STUDENTS UNIT 1

CASE STUDY 1: KHADIJA SICKLE MALADY by Khadija Njei



Heirlooms and family
Inheritance are handed
Down from generation
To generation as time moves on and centuries go by
Yes, so is sickle malady
Handed down like a fortune
Passing through genes
A plague inherited by the innocent ones
Sickle malady lives on As an album would
Pending on the memories That lie within
It sucks the blood to survive
It eats away at the immunity
That protects against other maladies
And it's still not happy
Until it is handed down to
The next and the next
And the next Sickle malady reigns supreme.
In the end, sickle malady
Kills its host
Yes, there is no happy ending
But soon I promise you
Sickle malady, soon it
Will be your turn.

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Khadija is 19 years old and lives in London. She is a practising Muslim and has a strong interest in both poetry and prose

QUESTIONS

Khadija is writing about a genetic condition called Sickle Cell Anaemia. Find out more about Sickle Cell Anaemia from the Genetic Condition Card you have been given, and be prepared to tell the rest of the class at least three things you have found out about the condition.

- Look at Khadija's poem again. Which does she feel has more power at the moment — Sickle Cell Anaemia or the people affected by it? Does she think this will always be so?
- Khadija's poem paints a fairly bleak picture of Sickle Cell Anaemia, but many people with the condition lead ordinary lives and keep painful 'crises' to a minimum.

Imagine that a student in your class has Sickle Cell Anaemia. This student is usually well but has missed a few days of school during the year. What can you and your teachers do to make sure that this student has the same opportunities at school as everyone else? (The information on the Genetic Condition Card you have been given might help you answer this question.)

ACTIVITY SHEET AND CASE STUDIES FOR STUDENTS UNIT 1

CASE STUDY 1 KHADIJA (continued)

As well as people who have Sickle Cell Anaemia, there are many 'carriers' of the Sickle Cell trait. Carriers have one faulty and one working copy of the Sickle Cell gene. They do not have Sickle Cell Anaemia and many do not even know they carry the faulty copy of the gene because the working copy of the gene masks its effects. So they are perfectly healthy, but they could pass the faulty copy of the gene on to any children they may have.

- Would you agree to be tested to see if you were a carrier of the Sickle Cell trait?
- What difference might it make to your life to know that you are (or are not) a carrier?
- Do you think everyone should be screened to see if they are carriers?

ACTIVITY SHEET AND CASE STUDIES FOR STUDENTS UNIT 1

CASE STUDY 2: HIFSA

Hifsa is 31 years old. She is married with a 5 year-old son and is pregnant with her second child. She came to this country in 1965 from Pakistan with her parents and five brothers and sisters and now lives in Stafford. Until recently, she worked as a Genetic Fieldworker at Birmingham Women's NHS Trust Hospital.

Q. What attracted you to the job of Genetic Fieldworker?

I've always wanted to work with ethnic minorities. When we lived in Leicester, I worked with black and minority groups to find out what they wanted from local cancer care services. Then we moved because of my husband's work and I saw this job in Birmingham for a Genetic Fieldworker to work mainly with Pakistani families. Obviously I had very little knowledge about genetics at the time, but I learned fast because I had to!



Q. Tell me a bit more about your work.

The project I am involved with came about because of a study published in 1993. It found that deaths and chronic illnesses in children were twice as common in families where the parents were of Pakistani origin. Families where there were many first cousin marriages were particularly affected. So it was decided that some work was needed within the Pakistani community to educate families about genetic disorders.

Q. Why are first cousin marriages a problem?

They're not! But genetically, first cousins who marry and have children have an increased risk of having a child with a genetic disorder, particularly if their parents were also first cousins. You see the chances of two parents both having faulty copies of the same gene and passing these faulty genes on to any children they have are usually quite small. But first cousins are likely to share some genes because they are closely related, so it is more likely that they will also share some faulty genes which they could pass on to their children. Take Thalassaemia, for example. If each parent carries the faulty gene and passes it onto their child, that child will have no working copies of the gene and will be affected by Thalassaemia. But Thalassaemia is a recessive condition (you need two copies of the faulty gene to be affected), so the parents (who each have one faulty gene and one working gene) are fine and might not even know they are carriers.

Q. It must be difficult going into your own community with information which people don't really want to hear. How have people reacted?

There were a lot of misunderstandings about the project at the beginning. People assumed that the idea behind the project was to teach the Pakistani communities that marrying your first cousin was bad for your health. Now that isn't what the project is about. I'm from the Pakistani community, my own family are married to first cousins, and I can't see that anyone has the right to go in and change a community's attitudes. Marrying your first cousin is not illegal. Okay, people have to be aware of the facts, but that's all our role can be. We can give them the information and then it's up to them to make an informed choice.

ACTIVITY SHEET AND CASE STUDIES FOR STUDENTS UNIT 1

CASE STUDY 2 HIFSA (continued)

Q. Can you describe a typical day?

Not really as there isn't one! I have a base in the Clinical Genetics Unit, so some days I'll go into the office and perhaps try and put together education packs for when I go out into the community to run health events or talk to groups of people. Or one of the consultants might ask me to go and visit a non-English-speaking couple and perhaps take a medical family history, or find out if they are having any problems understanding the information they have been given

Q. What do you like best about what you do?

When I come away from a family I've been visiting, they're usually smiling and they're just so grateful that somebody's actually taken the time to listen to them. I've had lots of families say, 'We were very relieved when you rang — it's so nice to be able to talk to somebody in our own language and tell you exactly how we feel'. And they often tell me things which they haven't mentioned to anyone else, so I think maybe I am helping and that's really what it's all about.

Q. What's the worst thing about the job?

When I have to break bad news to people. If there's a communication problem, some families put a sort of blanket over the information they've been given. They tell themselves that they haven't understood or they've got it wrong. But when I give them the information in their own language, there's no escape. They may not want to hear what I'm saying but they can't avoid it. I'm confirming their fears. So when I have to tell somebody that there is a problem with their family, or a particular problem with a child, it's really sad because I know that I'm telling them in such a way that they will understand.

Q. Do you offer emotional support to families?

I do, yes. I can go out to families and be there for two hours or more because I don't feel comfortable coming away until I know that they've got it all off their chest. I went to a family a few weeks ago and after about 15 minutes, both the mother and father were crying their eyes out, but when I left a couple of hours later, they were laughing and joking and chatting about different things to me.

Q. Has your job changed you at all?

I think it has. I mean at one point I used to think oh yeah, you get pregnant, you have a baby and everything in the garden's rosy, but I can't take the idea of pregnancy and childbirth lightly any more. It's quite a humbling experience to see what families go through bringing up a child with thalassaemia, for example. Some families are bringing up two or even three affected children because their beliefs mean that they won't have a termination. When I see the dedication and the amount of time and love and effort they're putting into what they're doing, it amazes me. I look at them and think I couldn't do that.

Q. What are your hopes for the future?

To have a normal, healthy baby!

ACTIVITY SHEET AND CASE STUDIES FOR STUDENTS UNIT 1

CASE STUDY 2 HIFSA QUESTIONS

Hifsa talks about a genetic condition called Thalassaemia. Find out more about Thalassaemia from the Genetic Condition Card you have been given, and be prepared to tell the class at least three things you have found out about the condition.

Hifsa says: 'Okay, people have to be aware of the facts, but that's all our role can be. We can give them information and then it's up to them to make an informed choice'.

- What 'facts' do you think Hifsa tries to make the families she works with aware of?
- What are some of the 'choices' families might face after Hifsa has talked to them?
- Do you think she's right to give people information and let them make the choices?
- The interviewer says, 'It must be difficult going into your own community with information which people don't really want to hear'. Why might the families Hifsa works with 'not want to hear' the information she gives them?
- Hifsa describes how she feels about her work. Be prepared to summarise what she likes and dislikes about her job. Would you like to do a job like hers which involves giving people information and using counselling skills? Why/why not?

ACTIVITY SHEET AND CASE STUDIES FOR STUDENTS UNIT 1

CASE STUDY 3: RICHARD

Richard is 15. He has two brothers aged 7 and 18. He goes to a residential special school in Coventry and comes home at weekends and holidays. His favourite subject is history but he hates maths. He loves football, both as a player and supporter. He has a genetic condition called Laurence-Moon-Bardet-Biedl Syndrome (LMBBS for short).



Q. Do you have tunnel vision?

Yeah. I can see a little bit in the middle but not things at the side...If I turn my head I can see a bit of what's there, but it's not as good as looking at something through the middle.

Q. So can you watch television?

Yeah, but I have to sit really close

Q. I know that one of the effects of LMBBS is restricted vision. Have you had problems with your vision all your life?

Since I was 3 or 4 — I used to bump into things.

Q. Do all your friends know you have LMBBS?

Yeah. I've got a lot of friends at school and they know.

Q. Do you want people to know?

I suppose I do want them to know really. In a way,

I think it makes it easier because then more people are going to know what it is, aren't they?

Q. What's the worst thing about having LMBBS?

Not seeing things properly.

Q. Are there any good things about it?

I suppose so. I mean people who can't see are called special people where other people are just normal.

Q. And do you feel special?

I do in a way, yes

Q. Do you think you are a healthy person?

Yeah, in a way, because I play a lot of sport. I go to swimming club and we play games and do gym and athletics and stuff. And I play football as well obviously.

Q. Do you think you're different?

Yeah. I feel special. But other people can do some things I can't do

Q. What about the word disabled. Do you think you're disabled?

In a way, yeah. Because I can't walk very easily because of my vision.

Q. Do you get aches and pains from walking?

I have done before, yeah. I get cramp in my feet and my hand — it's horrible.

ACTIVITY SHEET AND CASE STUDIES FOR STUDENTS UNIT 1

CASE STUDY 3. RICHARD (CONTINUED)

Q. Do you think you're an unlucky person?

Not really.

Q. And what about happy?

Yeah, I am.

Q. What are the sort of things that makes you unhappy?

When things go wrong really. At school or at home

Q. What's the best thing that ever happened to you?

Going to see Arsenal play Bolton at Highbury.

Q. Did they win?

Yeah, in the end. And they got into UEFA.

Q. What's the worst thing that ever happened to you?

There isn't one really.

Q. If you could have one wish, what would you wish

To be able to see



QUESTIONS

Find out more about Laurence-Moon-Bardet-Biedl Syndrome (LMBBS) from the Genetic Condition Card you have been given. Be prepared to tell the rest of the class at least three things you have found out about the condition.

Imagine that you are Richard's mother or father. You already have one son when Richard is born. As Richard grows up, he has problems with his eyes, his kidneys, his weight (his body cannot burn off calories properly so he is overweight) and he has mild learning difficulties. He is eventually diagnosed as having LMBBS. You discover that he has this condition because he has inherited no working copies of a certain gene, instead he inherited a faulty copy of the gene from each of you. Neither of you had any idea that you each carried a copy of the faulty gene for this condition. How do you think some parents feel when they learn that their child has a genetic condition?

ACTIVITY SHEET AND CASE STUDIES FOR STUDENTS UNIT 1

CASE STUDY 3 RICHARD (continued)

Getting information about rare genetic conditions can be difficult. Richard's mother got round this problem by starting a support group for people affected by LMBBS and their families, which is now a registered charity. Do you know of, or belong to, any support groups? How do they work? Do you think they help people?

Richard's mother wanted more children. But after Richard was born, she found out that there was a 1 in 4 chance that each and every baby she had would have LMBBS. She and her husband decided to try for one more baby and she became pregnant again. There is currently no test which will clearly show if a fetus is, or is not, affected by LMBBS. What sort of feelings do you think she and her family experienced during the pregnancy?

ACTIVITY SHEET AND CASE STUDIES FOR STUDENTS UNIT 1



CASE STUDY 4:CHRIS

Chris is 24 and lives in Hertfordshire. He has just completed a university degree course. Chris has a genetic condition called Glycogen Storage Disease (GSD). There are as many as 11 known types of GSD. Chris has Type IX, which is one of the least severe forms of the disease. His young nephew is also affected with GSD Type IX.

I thought I would tell you my story because I am sure that I am not the only scientist who has a strong personal link with my work.

I have a mild form of Glycogen Storage Disease (GSD). From about 1976—1987, I was seen by Professor Leonard at Great Ormond Street Hospital. Then in November 1992, I was asked by another doctor called Dr. Lee to take part in a study on adults with GSD. During several interviews, we chatted about all sorts of things including my job. I told him that I had just left school and was working as a laboratory technician in Watford.

A few months later I wrote to Dr. Lee to see if there were any openings for a lab technician at Great Ormond Street. To my surprise, he asked me if I would like to work at the Institute for Child Health for six months on the GSD research. I jumped at the chance to work on a disease so very close to home and in such a world-renowned research institute

During my time there I worked in the laboratory extracting DNA from GSD blood samples, doing enzyme tests and tests on urine. I even got to see what my own DNA looks like — not many people can say that! In all my visits to the hospital as a child I never thought I would end up working there, least of all working for the doctors I used to see as a child. It was a strange feeling walking around the hospital, although I have to say that my memories of Great Ormond Street were highly favourable and I always remember how caring the staff were. Sometimes I would remember a smell (hospital food or just the hospital smell) and get butterflies in my stomach. I did wonder when I started work whether I would be a sort of human guinea pig in constant demand for blood samples. Thankfully no-one ever asked!

I've just graduated from King's College in London with a degree in biological sciences and would like to return to some form of medical research. I know that in the media, scientists are portrayed as mad boffins or uncaring careerists. I like to think that having GSD myself, I brought a different perspective to the work I did. So next time you think of scientists working away, remember that at least.

QUESTIONS

- Find out more about Glycogen Storage Disease (GSD) from the Genetic Condition Card you have been given. Be prepared to tell the rest of the class at least three things about GSD.
- Chris enjoyed researching into GSD. But can you think of any problems which might arise for someone doing research into a genetic disorder which they or their family are affected by?
- If you had GSD or any other genetic condition, would you want to find out as much as you could about the condition? Why/why not? Would you want everyone to know that you had the condition? Why/why not?