Human genetics:

Debate of a personal dilemma

UNIT 7

European Initiative for Biotechnology Education

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The European Initiative for Biotechnology Education (EIBE) seeks to promote skills, enhance understanding and facilitate informed public debate through improved biotechnology education in schools and colleges throughout the European Union (EU).

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World Wide Web

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With this software, you can view or print the EIBE Units. In addition, you will be able to 'navigate' around and search the documents with ease.

Unit 7: 2nd edition (modified 4/98)

Development

This debate 'game' was originated by Katrine Drumm, Allan Wege and Christina Christensen for *Eksperimentarium*, the Danish science centre in Copenhagen. It was one of the contributions to the *European Week for Scientific Culture* in 1994, under the heading of 'European debate games on biotechnology'. Four 'games' or debates were included; two concentrating on discussions on a personal level and two on a socio-political level. The first two 'games' were translated from Danish into English, French, German and Swedish.

The activity in this EIBE Unit is one of the first 'games': a dilemma on a personal level. It has been used throughout Europe, involving more than 1,000 students and 40 teachers and debate leaders in Belgium, Denmark, Germany, Ireland, Luxembourg, The Netherlands, Sweden and The United Kingdom. On the basis of these experiences, the teacher's guide to the debate has been revised by members of the EIBE team.

The materials are now also available in Dutch and French.

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ABOUT THIS UNIT

Introduction

These materials have been devised by practising teachers and educationalists from several European countries, brought together with financial support and encouragement from DGXII of the European Commission, under the auspices of EIBE, the *European Initiative for Biotechnology Education.*

The EIBE materials have been extensively tested in workshops involving teachers from across Europe.

The views expressed in this Unit and the activities suggested herein are those of the authors and not of the European Commission.

Objective

The objective of this debate game is to generate discussion on the use of genetic engineering technology on people and human embryos.

Target group

This debate game is aimed at young people between the ages of 15 and 20 with a good education and an interest in society, biology, technology and ethics. A basic knowledge of heredity and the role of genetics is assumed. The debate game can be used in biology, philosophy, religion or social science classes.

The game

The debate game is a discussion or debate exercise, where participants are placed in a situation that forces them to take a position on the use of biotechnology, at a personal level. By placing the debate game's reality some years in the future a more objective and exciting basis for discussion is created. The data, issues and input participants are confronted with become a mixture of fact and fiction. The fictitious element is not the result of wild imagination, but is based on an informed projection of scientific and technical developments. We would recommend that participants be made aware of this from the outset, but are not told what are facts and what are not before the end of the game.

A list of what is true and what is invented, as of late autumn of 1994, is included in the document "Fact or Fiction".

A suggested lesson plan

Lesson 1

- Introductory Evaluation Questions (Optional - see Appendix).
- Read aloud or summarize "Introduction for lesson 1" from **Guidlines for the teacher**.
- Distribute *Student Package 1* "Genetic Disorders in the Year 2005", to be read as background before lessons 2 and 3.

Lesson 2

- Divide the class into groups of 4 or 5 students using genetic characteristics.
- Read aloud to the class "Setting the Scene".
- Distribute *Student Package 2* to each student.
- Distribute *Student Package 3* to each group.
- Each group debates the issues and completes the questionnaire (*Student Package 3*) as a group.

Lesson 3

- A class debate of the positions taken by each group.
- Consideration of "Further Issues" (Optional - see Appendix).

Lesson 4

- "Fact or Fiction" - a biology debriefing explaining the present state of knowledge as to what was fact and fiction in the game.
- Final evaluation question (Optional - see Appendix).

Guidelines for the teacher

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Fact and Fiction?

To formulate a debate game of this nature, the organizers were obliged to imagine that we are actually a few years hence in time. The information you will be given, therefore, is a mixture of fact and fiction. Today it is possible to find the gene that causes cystic fibrosis through amniocentesis (testing the amniotic fluid in the womb during pregnancy) - *See EIBE Unit 4*. It is also possible to undertake genetic engineering on lung cells to relieve chest conditions. During the course of the debate game you can maybe imagine that science has identified the genes responsible for baldness, manic depression and obesity, and has the power to change them. Maybe science will not have identified precisely these 3 genes in ten years time. On the other hand, science will, without doubt, be aware of 20, 50 or 500 others. During the debate game you must assume that all the information you receive is in fact correct. What is fact and what is fiction, here and now, will be returned to later.

Formation of groups

The following characteristics have been found to work well for dividing the students into groups:

- Left/Right thumb uppermost when hands are joined
- Earlobes, pendulous/enclosed
- Hair, straight/not straight
- Right handed/Left handed
- Eye colour
- Hair colour

Introduction for lesson 1

To be read aloud or summarized for the students before the distribution of Student package 1

The game you will play next lesson is a debate on biotechnology, as it directly effects human beings in the year 2005. It is not a game of dice but an introduction to discussion. In this game you will discuss and then take a position on the ethical and moral implications presented by the possibilities of genetic engineering.

At the moment we are obtaining greater and greater knowledge of human genes and increasingly refined technical ability in the area of genetics. Quite soon it will be possible to read a mass of characteristics in genes and in the forseeable future to change these genes. An amount of progress has already been made, including mapping and treatment possibilities of numerous hereditary diseases. It is easy to recognize the positive effects, as they relate to the effective treatment of hereditary conditions. It is just as easy to see the danger of manipulation of human genetics, previously existing only in the realm of science fiction. In the real world we must hold our own on the tightrope between scientific and technical possibilities on the one hand, and ethical correctness on the other. It is imperative that we be involved in the decision making process, decisive to future society and peoples. These critical decisions cannot be left soley to the experts.

How will we utilize these new advances in biotechnology? Possibilities are opening up in all directions. In a democratic society we can be involved in mapping the course of developments and laying down guidelines as to which type of technology should be used and when. You are getting your chance here. The discussion is not simple. There is almost an infinite number of factors involved in this issue. A few hours debate will never suffice. Neither is this the intention. The idea of this debate game is to set off a chain reaction, leading to further discussion. You may use it in connection with subjects you are studying at school. You can talk to your parents or friends about it tonight. You can read newspaper articles on the issue with new awareness, and so on.

Setting the Scene

To be read aloud by the teacher before the distribution of Student package 2.

Imagine we are in the year 2005. You and your partner are expecting a baby. You are 6 weeks pregnant. You have just been to the Smalltown Hospital for your first examination, and everything looks normal. You have been offered a genetic test of the embryo. In the year 2005 this type of test has become common place and most people accept them without question.

You are now asked to discuss what information (if any) you would like to receive from this genetic test and to enter your groups decisions on a questionnaire. To help you consider the issues you will be given 3 newspaper articles presenting different points of view.

Further Issues

Additional examples may be considered here (see Appendix).

A biology debriefing

The information given here will obviously change with time but was accurate in autumn1994.

General: Twin Studies

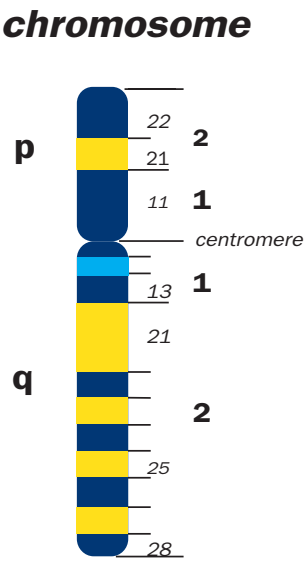
Twin studies compare the occurrence of a particular illness/characteristic among identical twins with those of fraternal twins. The basic assumption in such a study is that identical twins share the same genetic makeup, while fraternal twins, on average, have only half their genes in common, as have ordinary brothers and sisters. At the same time both twin types are exposed to the same environmental factors, before and after birth. Heredity plays a decisive role in the appearance of a particular illness/ characteristic, in that, concordance is more often expected in the case of identical twins than in the case of fraternal twins.

General: Embryonic Tests

Amniocentesis (removal of amniotic fluid for diagnostic purposes) and testing the placenta are common when carrying out genetic studies of the embryo. Amniocentesis is carried out in the 17th week of pregnancy and the placenta test in the 9th week. Research continues into genetic test methods, at an even earlier stage in pregnancy.

General: Naming Genes

Genes identified through the HUGO project are named according to placement. A gene's name is arrived at according to the chromosome it finds itself on, whether it's on the long or short "arm" of that chromosome and which band it stretches over. Examples are: 7q31,3-q32 (cystic fibrosis) and Xq28 (colour blindness). This method of naming is, however, not unequivocal in that many genes can have the same placement. Besides the 3 genes causing colour blindness on Xq28 there is, for example, a gene possibly connected to manic depression, 2 genes for different types of mental retardation, a gene for a particular type of diabetes, and others. For example:



In this debate game we have chosen to name genes in another manner. We have done this because often there is no connection between the stories presented to participants and genes in fact identified. In this game a gene has a name of the type 7-9kj or x-3pl, where the number/letter before the dash denotes the chromosome.

Alcoholism
No gene has been found for alcoholism. Information contained in the folder has been compiled against the background of the twin and adoption studies. These studies reveal that adopted sons of alcoholic fathers have a 4 times greater risk of developing alcoholism than adopted sons of non alcoholic fathers.

Cystic Fibrosis
Cystic fibrosis is one of the most common congenital disorders in the western world. The gene is recessive which means that only people with 2 examples of the gene will develop the illness. The cystic fibrosis gene has been identified and research continues as to the feasibility of treating the disorder by means of genetic engineering. This is one illness where great store is put on the effectiveness of genetic engineering treatment.

Homosexuality
No gene has been found for homosexuality. Research continues in the USA to ascertain whether or not homosexuality is genetically determined.

Huntingtons Chorea
The gene for Huntingtons Chorea, a dominant heritary illness, has been identified. The embryo can be tested for the disorder. Tests are usually offered to families with a history of the illness. Huntingtons Chorea only occurs in families with a history of the illness.

Manic Depression
The information available in this folder is based on the results of the twin studies which indicate that the development of manic depression is genetically determined. 7 different twin studies conclude that concordance for manic depression psychosis is 68% among identical twins brought up together, 67% for identical twins brought up apart and 23% for fraternal twins. Two genes have been identified as possible determinants of manic depression. The gene named in this folder has no bearing on these two genes.

Gender
This test not only exists but is used on a regular basis. It is particularly useful when there is the possiblity of a sex-linked disorder.

Obesity
Numerous genes have been found to have a bearing on the tendency towards obesity. All other information in the folder on this point is fictitious. When a family member talks in terms of obesity being hereditary, it is advisable to note the dimensions of the family dog...

Diabetes
It is not possible at present to test the embryo for a later development of diabetes as no single gene has been found as a cause for the disorder. Studies have shown that several genes are involved and among them tissue type genes (HLA genes of various kinds). Different environmental factors are also important. On average unrelated people have a risk of developing diabetes of 0.5%. The risk goes up five times to 2.5% if they have two HLA genes in common. The risk of developing the disorder for a brother or sister of someone with diabetes is 6% and the risk for a child with one diabetic parent is 4%.
A recent twin study (Kyvik et al reported in the BMJ 1995 Oct 7) has shown that concordance for identical twins is 70%, with 13% for fraternal twins. Based on these findings the genetic component to the disease seems more important than previously thought. However the concordance for fraternal twins is higher than for ordinary brothers and sisters implying that the environment also plays an important role in the development of diabetes. Fraternal twins are exposed both in the embryonic stage and during growth to more uniform environmental factors than other brothers and sisters.

Appendix

Evaluation questions

If the teacher and students wish to evaluate what they have learnt in this debate game the procedure outlined below has been shown to be useful.

The evaluation is carried out in two steps.

At the beginning of Lesson 1 the students are given the following instructions.

1. Please write down as many words as you can think of that are associated with prenatal testing.

   Do not take more than 3 minutes.

2. Rearrange your words in groups with connected meaning. Add any new words to a group that come to mind. Number the groups.

   Do not take more than 3 minutes.

3. (This is the last and most important part).

   Formulate one or two sentences to show the connection between each group of words and 'Prenatal testing'. Label your sentences with the numbers of the word groups.

   5 minutes should be sufficient time.

   Put your name on the paper and hand it to your teacher. These papers will be returned to you at the end of the debate game for evaluation.

After finishing lesson 4 hand out the papers again to the students and ask them to comment on their statements as follows:

- What new words would you add to your list?
- Do your groupings of words still seem logical?
- Assess your sentences. If you had to redo this exercise how would your sentences change?
- If you had an opinion about 'prenatal testing' before the debate game has it changed in any way? If so, could you explain what caused the change?
- What is your opinion of this debate game?

We would be very pleased to receive any comments from teachers. Please address any comments or questions about this debate game to:

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Further Issues

In an article entitled *'DNA Dilemmas'* in *Science News* three interesting cases were presented for discussion.

1. A couple who both have achondroplasia, an inherited form of dwarfism, desire a dwarf child. They tell the genetic counsellor they will abort a foetus destined to grow to normal height. Should the centre perform the test, knowing the couple´s intent?
2. A couple who already have a child with cystic fibrosis (CF) seek genetic counselling. They want to know the risk of having another CF child. Routine screening tests show that the husband is not the biological father of the child. What should each of them be told?
3. A pregnant woman worries about her family history of fragile X syndrome, an inherited form of mental retardation controlled by a recessive gene. She tells the counsellor at a genetic testing centre that she intends to abort if the foetus is a carrier of the trait and thus likely to be healthy, but capable of passing the defective gene to the next generation. Should the centre perform the test, given the patient´s stated intent to abort an otherwise healthy foetus?

Science News (1994) Volume 146, page 408 "DNA Dilemmas" by Kathy A. Fackelmann.

Economics

Some of the prenatal tests will be cheap, others more expensive but if one thinks of screening for all the possible disorders at the same time it can be an expensive programme to run. The first private companies have already shown interests in carring out these tests. National borders are no limit any more. It is easy to post a blood sample to a laboratory where else in the world so tests like these can easily be carried out somewhere else.

As the trend in most European contries is to cut down on health expenses should the tests be made available under national insurance cover or should the public pay privately for them?

STUDENT PACKAGE 1

Genetic disorders in the year 2005

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Alcoholism

In this test we offer you information on the increased risk of alcoholism. Alcoholism develops in a complicated pattern, where both hereditary and enviromental aspects combine as components. We will test for the presence of a single gene (y-4kf). There are numerous genes influencing the development of alcoholism, but y-4f has been shown to have the highest direct influence. Tests indicate that the presence of y-4kf quadruples the risk of a man developing alcoholism. It should be stressed, however, that a person can become an alcoholic without being a bearer of the y-4kf gene.

Awareness of the occurance of the y-4kf gene gives parents the possibility of preventing alcoholism, by promoting healthy and sensible alcohol habits as the child grows up.

y-4kf is found on the y-chromosome a male embryo inherits from his father. If the embryo has y-4kf, the same increased risk of developing alcoholism will also apply to the child's father.

Cystic Fibrosis

Cystic Fibrosis is a cellular condition where the mucous glands contain less water than normal. This in turn affects many body functions. The respiratory tract becomes chronically infected, resulting in frequent chest infections. Pancreatic insufficiency complicates the digestion of proteins and fats.

Patients suffering from cystic fibrosis must undergo intensive treatment all through life. Treatment consists of inhaling mucous loosening preparations numerous times a day, followed by breathing exercises and psysiotherapy. In addition, the patient must take medication containing digestive enzymes with meals to ensure the digestion of fat. Due to frequent chest infections, most patients spend about two months in hospital every year.

This gene test determines beyond any shadow of a doubt whether or not the expected baby will develop cystic fibrosis. We test for the illness bearing gene 7-9kj. Cystic fibrosis is inherited recessively, which means, the embryo must inherit the illness bearing gene from both parents to be affected. Parents, therefore, are bearers of the gene. In other words, they have the gene without any manifestation of illness. In the west one out of 25 people are carriers of the cystic fibrosis gene. The condition occurs in 1 out of every 2,500 new born babies. Cystic fibrosis, therefore, is one of the most common inherited conditions.

Homosexuality

In this study we offer you information on the increased likelihood of homosexuality among men. Homosexuality develops in a complicated pattern. In this study we test for a single gene, x-3pl. The gene is present in the x-chromosome the embryo inherits from his mother. Presence of the x-3pl gene trebles the likelihood that a man will be homosexual. 1-5 percent of the male population is homosexual.

It must be stressed, however, that homosexuality can also develop in men who do not have the x-3pl gene. As far as can be estimated at present there are a number of genes influencing the development of homosexuality. Psychological factors also play a role. Many of these factors have not, however, been clearly defined, as yet.

Huntingtons Chorea

Huntingtons Chorea can be most accurately described as a type of convulsion of the brain. Initially the patient suffers irregular brief jerky movements of the arms and legs, complicating mobility. Those affected suffer a personality change becoming increasingly negative and uninterested in their surroundings. Patients die after 15-20 years in a completely helpless condition, physically and mentally wasted. In most cases the disorder develops between 35 and 50 years of age.

Huntingtons Chorea is a severe inherited condition. It will develop if the embryo is carrying even one example of the 4-4tt gene.

NB: The 4-4tt gene can be inherited from the father or mother. If results show that the embryo has the gene it also indicates that one parent will also develop Huntingtons Chorea. The likelihood of an embryo carrying the Huntingtons Chorea gene is very remote, if there are no previous incidences of the condition in the family.

Manic Depression

Manic Depression manifests itself in periods varying from a few weeks to many months. The symptoms are either mania or depression. Manic depression usually appears between 30 and 50 years of age, but can also occur earlier or later.

In the manic period everything occurs at an exaggerated speed. The patient becomes euphoric and is overwhelmed with ideas that never come to fruitition before a new idea presents itself as more exciting. The patient sleeps and eats too little, is excessively self confident, lacks self criticism and a sense of reality and does not perceive himself or herself as ill, complicating treatment.

In the depressive period the patient suffers sadness and lacks confidence. The patient's self confidence and energy debilitates so even mundane every day activities seem unsurmountable. The patient has a deep desire to relieve his or her mind by crying, but is unable to shed tears. The muscles become slack, movement lethargic. The patient may suffer constipation and, in the case of women, amenorrhoea (abnormal absence of menstruation). The patient often attempts suicide.

The extent to which a patient is affected by manic depression varies quite considerable. Some suffer a single bout of depression, while others are afflicted with innumerable attacks of depression and mania. The condition is treated with various types of medication and in some cases electroconvulsive therapy is administered. It is impossible, however, to prevent new attacks of mania or depression occuring.

Manic depression develops through a complicated interaction of heredity and environment, involing many unknown factors. We offer to test the embryo for the 3-9sh gene. If the embryo has this gene, there is a 30% risk that it will develop manic depression. In the rest of population not bearing the gene the risk is 1-2 percent.

Gender

The embryo's gender can be determined in many tests offered to pregnant women. Gender is unequivocally determined in this test.

If incidences of inherited diseases in your family are related to gender chromosomes, it can be of great advantage to know the gender of your embryo.

Certain inherited conditions and disabilities, like haemophilia and colour blindness, occur predominantly in boys/men. This is because the gene in question here is found in the x-chromosome. Men have one x-chromosome and women two. If a man has the gene, he will automatically develop the disability. Women must have the identified gene in each of the two x-chromosomes to develop the disorder. In addition, a few conditions are related to the male y-chromosome.

Obesity

Obesity occurs through a complicated interaction between heredity and environment. In this survey we offer information on the presence of the 14-9gb gene, which results in the increased risk of obesity. Among Europeans as a whole 5 percent of population are severely obese. Among people carrying the 14-9gb gene 50 percent are severely obese. It must be stressed, however, that obesity can occur in people who do not have the 14-9gb gene.

Obesity can be a major physical and psychological problem for sufferers. Knowledge of the presence of the 14-9gb gene affords parents the opportunity of influencing the child's life style so that obesity is prevented, or at least limited. Parents can, for example, ensure that the child eats a healthy diet and is encouraged to take regular exercise from the outset.

Diabetes

Insulin demanding diabetes occurs when the body is unable to produce insulin. Insulin is a hormone essential to the cells' absorbtion of sugar. When the body produces insufficient or no insulin, sugar accumulates in the blood and is excreted in the urine. The condition usually manifests itself before the patient reaches 30.

Insulin demanding diabetes is incurable and must be treated throughout life with daily insulin injections. Diabetics must adhere to a strict diet. Patients often experience problems with surface ulcers that will not heal, and run a higher risk of developing circulation disorders, blindness and kidney failure. If blood sugar is not regulated exactly within precise limits, the brain cells are affected and the patient loses consciousness. About 4% of diabetics die due to inconsistency between the amount of insulin administered and that required. The diabetic must lead a well ordered life, exercise regularly and eat 4-5 meals daily, to ensure that energy is divided evenly.

In this survey we are testing for the presence of the 18-2jd gene, which increases the likelihood of the development of diabetes to 0.7% , if inherited from both parents. If the embryo has one example of the gene, the risk is 0.25 %. It is also possible to develop diabetes mellitus without the presence of the gene. Here the risk is 0.02 %.

Results will show whether the embryo has one, two or no examples of the 18-2jd gene.

STUDENT PACKAGE 2

A letter from Smalltown Hospital

Open letter to a pregnant couple

12th August 2005

Smalltown Hospital is participating in an EU financed research project, designed to determine various genetic characteristics and the extent of illness in various regions of Europe. You are being offered an opportunity to participate in this research project, which involves the acceptance of a genetic test of your embryo.

After four weeks of pregnancy it is possible to find embryo cells in the mother's blood. The examination demands only a simple blood sample. Embryo cells can be separated and examined further. The examination, therefore, poses no risk either to the mother or embryo.

By examining the genes of embryo cells it can be determined if the embryo is suffering from a serious illness, or is disposed to such illness that may manifest itself later in life. Today, we have a wealth of knowledge of human genetics, thanks to the successful implementation of the HGP (Human Genome Project).

In this EU survey it has been decided to test for the genetic characteristics described below. If you wish to participate, you must choose which results you wish to have. The survey will test the embryo for all genes on this list. Those results you don't wish to be made aware of, however, will remain anonymous.

The choice, of course, is yours. Your obstetrics treatment will in no way be effected by your decision. All results will be treated in the strictest confidence. There is no risk of misuse at a later stage. The survey has been approved by the Council of Professional Ethics and is being followed closely by a special commission set up by the Ministry of Health.

With best wishes

Betty Hayes

Betty Hayes
Survey Organiser

John Owen

John Bray Owen
Specialist

You are our Genes

July 2005

Thomas Levy, News Correspondent

A shudder went through the court room when judgement was delivered on a sensational and dramatic action for damages at the High Court in London, yesterday. The case involves 8 year old Jonathan Miller, son of bank director William Miller and the world renowned opera singer, Lena Raven. Jonathan is brain damaged as a result of medical error at birth. Jonathan will never reach a development level higher than a 2 year old. He was awarded record damages of £1.2m.

In recent months the case has revived scientific debate as to what extent heredity or environment determines human development. The family's solicitor summoned the German genetic researcher, Professor Franz, whose evidence developed into a lengthy monologue. When giving evidence he referred to the 'twin studies' he has been working on in recent years. "Genes play a critical role in our development, he said. They are literally fundamental to our existence. We will have to forget all the romantic notions of the past which supposed we all have equal opportunity. From the point of view of nature we are created unequally!"

"Identical twins are genetically equal. They have, therefore, the same opportunities and limitations, he continued. Fraternal twins, on the other hand, are no more equal or similar than other brothers or sisters. In a survey of identical twin girls it has been found that if one twin is lesbian the other will also have a 48 percent of being lesbian as well. With fraternal twins the same coincidence only occured in 16 percent of cases. The conclusion, therefore, must of necessity be that our potential lies in our genes!"

When delivering judgement the judge placed a lot of weight on the professor's evidence and defended awarding record high damages, by referring to "the boy's good artistic and business genes".

Stop all Discussion on Genes

July 2005

Ann Owen, SRN

In recent years reference is frequently made to the 'twin study' in the debate on heredity and environment. Soon all human characteristics will be explained by reference to genetics. We hear one set of parents after the other disclaiming responsibility for their children's drug misuse, violence and lack of social adjustment. My own experiences as a twin leads me doubt these conclusions.

The entire basis of the twin survey is that identical twins have the same genes, while fraternal twins are no more similar than other brothers and sisters. If a definite behavioural pattern is found to be greater among identical twins than fraternal twins, we gradually begin to lean towards the extreme which presumes that this must be genetically determined. An example: if one identical twin is a criminal, so there is a 51 percent certainty that the other will also be. Among fraternal twins the likelihood is 22 percent. We are concluding, therefore, that criminal behaviour is hereditary?

Identical and fraternal twins, however, differentiate not only in terms of heredity. Upbringing is also different! Identical twins are usually brought up similarly. I can give many examples of this. They develop at the same pace, are interested in the same things and belong together in a way that I in no way recognize from my relationship with my twin brother. We were not brought up any differently than my other brothers and sisters: my brother played football with our father, took the dog for walks and dismantled everything from bikes to alarm clocks to computers. I, on the other hand, baked cakes with my mother, went pony trekking and learned how to knit.

If the environmental, or social effects, are recognized the statistics are suddenly turned upside down, so that the social rather then the alleged genetic effects are reflected in survey results. When, for example, we are considering alcoholism, criminality and mental illness, refrain from disclaiming responsibility by referring to genetics. Raise your children properly. Genes won't do it for you!

Should we know everything?

August 2005

Jane Brown Wessel, Laboratory Technician

One year ago my husband and I decided to terminate our pregnancy. Both my mother and cousin were manic depressives. We were, therefore, offered a genetic test of the embryo. Our expected child had, unfortunately, the manic depressive gene. It was very difficult to decide whether to have the baby or not. We had been trying, unsuccessfully, to get pregnant for years. My mother's condition was taking its toll. We were worn out. We felt we could not cope with more problems of that nature in the family.

The manic depressive gene carries a 30 percent risk that the child will develop the condition. There is of course still a 70 percent chance that the baby will be completely normal. Most studies also indicate that there are unknown social factors that determine whether or not the condition will manifest itself. In our case it was my husband's and my responsibility to give the baby the best possible upbringing to prevent the development of manic depression.

But how could we ever give the child a normal childhood? We would be concentrating all too heavily on doing the right thing. We would doubt our rearing methods and be for ever on the look out for even the slightest indication of mental imbalance. It was this awareness that finally led to our decision of termination.

Practically everyone is praising genetic testing. It is probably an advantage to test the embryo in cases of serious illness. On the other hand, there are also a multitude of results (being disposed to mental illness etc, etc) that expectant parents cannot relate to, making a decision infinitely more difficult. Of what benefit then is this choice, besides the fact that it makes you feel guilty.

One year later I am happily pregnant again and as a result of considerations made during the year, we have decided to have the baby without a product declaration. Have we reached the right decision? Only time will tell.

STUDENT PACKAGE 3

Questionnaire

1: For which conditions do you wish you wish to have the results?

	No	Yes
Alcoholism	❑	❑
Cystic Fibrosis	❑	❑
Homosexuality	❑	❑
Gender	❑	❑
Manic Depression	❑	❑
Obesity	❑	❑
Diabetes	❑	❑

Reach the broadest possible consensus within the group before answering this question. Only one answer for each condition.

2: Prenatal testing shows that your future child will not be of the sex you had hoped or will have one of the following conditions. How will this affect your attitude and behaviour towards the embryo?

	We would choose to terminate pregnancy	We would change our lifestyle if it helped	We would do nothing and let nature take its course
Alcoholism			
Cystic Fibrosis			
Homosexuality			
Huntingtons Chorea			
Manic Depression			
Obesity			
Diabetes			

3. If you choose not to abort, what do you think will be your attitude? Will you bring up your child in any special way? Will you seek any particular advice or assistance? Explain for each condition.

Alcoholism

Cystic Fibrosis

Homosexuality

Manic Depression

Gender

Obesity

Diabetes

4: What did you discuss most in your group?

5: Given the choice today, how many in the group would accept to take part in a survey of this type? Insert numbers in the boxes.

- ☐ YES, and I would request the complete results
- ☐ YES but I would only request some of the results
- ☐ YES for scientific reasons, but I would personally not wish to know anything about the genes of the embryo.
- ☐ NO, I would refuse to participate, because I object to this type of test.