Ethics in Genetics: Case Study Debate

You will be assigned a group and an ethical case study. Two groups will be assigned to each case study and to which side they will be representing.

Written Component:

Each group will answer **all** of the dilemma questions based upon their assigned position(s).

- As a group, **one set** of typed answers for all the dilemmas, including **citations & references**, will be handed-in to **before** the debate begins.
- Each group member must clearly indicate **one** of the dilemmas upon which their **individual** mark will be based (written & oral).
- A list of potential challenges opponents may present for **each** dilemma and appropriate rebuttal points must also be handed-in prior to the debate.
- Each group member must **individually** answer the follow up questions

Debate Format:

- The case study will be read to the class.
- A coin will be flipped to determine which group will go first. Turns will alternate for each dilemma.
- A dilemma will be read to the class. **Each** group will have **1 minute** to present their position regarding this dilemma.
- The class will vote after each dilemma.
- Each group will have **2 minutes** to make a final **summary** of their positions and **rebut** statements made by opposing group.
- Each group member must present the answer to the dilemma indicated in the written copy during the debate.

Group marks will be dependent upon the final rebuttal and peer voting after each dilemma.

- The class will be the representative jury for our society and will vote on and express society's current view on your topic, based on the arguments that you present. The more careful and well thought out positions; will probably sway the jury the most. Be ready to back up your statements with specific sources.

Assessment:

- **Individual** mark will be based upon the specific dilemma answered during the debate (written & oral answers) as well as answers to follow up questions.
- A **group mark** will be assigned based on the final rebuttal and class voting.

Remember that this is an exercise in which there is no right or wrong answer. The issues need to be discussed rationally by all members of the class.

Case Study _____ Dilemma _____

Name: _____ Group Members: _____

Individual Assessment Rubric

Criteria	5	6	7 8	9 10	
Understanding/ Knowledge of the dilemma being debated/ supporting arguments (oral)	Displays **limited** understanding of the topic	Displays **some** understanding of the topic	Displays **considerable** understanding of the topic	Displays **thorough** understanding of the topic	**/20**
of the ethics in genetics (written)	Viewpoints are **unclear** and **disorganised**.	**Some** viewpoints are **clear**	Most viewpoints are **clear**.	Viewpoints are very clear and **organised**.	
Application Relevance (oral)	Makes **minimal** use of persuasive **appeals**	Uses **some appeals** to make argument more persuasive, but may not include a mix of logical, emotional and ethical appeals	Uses logical, emotional and ethical **appeals** to **enhance** effectiveness of argument	Makes **deliberate** and **effective** use of logical, emotional and ethical **appeals** in order to persuade justices	**/20**
Relevance of supporting arguments (written)	Supported arguments with very **few relevant** facts or with irrelevant facts	Supported arguments with **some relevant facts**	Supported arguments with **several relevant** facts	Supported arguments with **many relevant** facts	
Communication Voice/Clarity (oral)	**Most** of the talk is **unclear** or **inaudible** to most of the audiences.	**Several** parts of the talk are **unclear** or **inaudible** to most members of the audience.	A **very brief** portion of the talk may be **unclear** or **inaudible** to some members of the audience.	Every spoken word can be heard and understood **clearly** with no difficulty by the audience.	**/30**
Audience engagement (oral)	Most of the time, the speaker is **not looking** at the **audience**.	The speaker **looks at the audience** part of the time. When looking up, there is **little** direct **eye-to eye contact** with members of the audience.	The speaker is **looking up** for **most** of the talk. The direct **eye contact** with members of the audience is **sporadic**.	The speaker is **looking at the audience** almost all of the time. The speaker makes direct **eye-to eye contact** with **most** of the audience.	
Terminology (oral)	Uses limited appropriate biology terminology and vocabulary	Uses some appropriate biology terminology and vocabulary	Usually uses appropriate biology terminology and vocabulary	Uses appropriate biology terminology and vocabulary throughout	

Group Assessment Rubric

Criteria	5	6	7 8	9 10	
Thinking/ Inquiry Quality of rebuttal (oral)	- rebuttal is mostly **ineffective**	- rebuttal is **somewhat** effective	- rebuttal is **effective**	- rebuttal is **highly effective**	**/20**
Preparation & anticipation of rebuttal (written)	- seemed **unprepared** for opponents' points and made few rebuttals	- adequate **preparation** for opponents' arguments but **needs stronger rebuttals**	- prepared for points by opponent and **responds proficiently** with evidence	- clear and thorough preparation for opponents points with **exceptional challenges / rebuttals** with evidence	
Voting results	< 10% of the vote	10-29% of votes	30-49% of votes	> 50% of votes	**/5**

Ethics in Genetics – Debate Follow Up Questions

Knowledge & Understanding (K)	1. What are some potential uses of decoding your personal genome? [2] 2. Describe some pros & cons of personal genome testing [2] 3. In what fields and for what purposes are GE used today? [2]
Evaluating (A)	4. Find a recent (< 3yrs) article stating a link between a particular gene and a behavior, condition or disease. Summarize the article in SEE method. [5] 5. Answer the "4 ethical questions" based on the article you summarized. **MAX ½ PAGE** [4]
Creating (T)	6. What rules or laws (3-4) should Canada have in place to ensure research conserving genetics is carried out ethically? Defend your decisions. **MAX ½ PAGE** [10]

Case Study #1: **Susan**

Susan, a 40 year old woman, embarked on a family research project. During the course of the research, she discovered other family members, hitherto unknown to her who lived abroad. While she knew that her mother had been diagnosed with breast cancer at age 43, she was unaware that her mother's five sisters and Susan's three cousins had also been diagnosed with breast cancer, some at relatively early ages. Given this history, she consulted her GP who advised her about the availability of genetic counseling and possible pre-symptomatic genetic testing. She informed the genetic counsellor that she did not want her mother or other family members to know she was having genetic testing.

The result indicated that Susan had inherited a predisposition to develop breast cancer that meant that she had a 40%-80% chance of developing breast cancer during her lifetime. Being a private person and because there was some discord within the family, Susan did not wish to discuss this result with other family members. She did, however, tell her 18 year old daughter who now has a 50% chance of having inherited the same faulty gene. She also asked that the genetic counselor inform her GP of the test result. When it was suggested that her three sisters and three brothers may also want to have information about their chance of having the mutated gene for predisposition to breast cancer, Susan indicated that she would not be communicating with them. Two years later, Susan's older sister, Barbara, who lived interstate, was diagnosed with advanced breast cancer. She was unaware of her risk for developing breast cancer.

Just after Susan had received her genetic test result, her younger sister, Mary, applied for life insurance. Susan and Mary are both patients of the local GP. The GP was asked to provide relevant medical information for the insurance policy. When asked about family history of cancer, Mary answered honestly that her mother had breast cancer but that there was no other family history. She was not aware of the research undertaken by Susan. She is also of course unaware of the result of Susan's genetic test.

Dilemmas:

1. Does the genetic counseling team, or a GP, have an obligation to inform Susan's relatives with whom they have had no previous contact that they may also be at increased risk, regardless of Susan's wishes?
    - What if Susan's sisters and brothers were also the GP's patients?

2. Regardless of legal issues, is the GP morally obliged to be honest to the insurance company about his knowledge of the family history?

3. If the GP does reveal the information about Susan to the insurance company, should the company use this information in the assessment of risk for Mary in underwriting any policies issued to her?

Case Study #2: **Mr. H**

Huntington disease (HD) is a neurological degenerative disease that has an onset in most people between the ages of 30 and 50. There is no cure for this condition and it is progressive. Features include deterioration in movement, cognition and generalized functioning. Death usually results from respiratory illness. HD is an inherited condition. A child of an affected person has a 50% chance of inheriting the faulty gene that causes the condition. Genetic predictive testing is now available for persons over the age of 18 who have an affected parent or relative which will tell them in almost all cases whether they will develop the disease at some stage in their life. Worldwide, of those eligible for the test, only around 15% of people have taken up the option of testing.

Mr. H. is a 25 year old man whose grandfather died some 10 years ago from Huntington disease. Mr. H's mother has therefore a 50% chance of developing HD. She decided to have the genetic test and has been shown to have the faulty gene. She will definitely develop HD at some time and Mr H is now at 50% risk of developing HD.

Mr H. is an air traffic controller. He loves his job and he feels he could perform his duties most adequately for many years, irrespective of whether he carries the faulty gene for HD or not. He does not wish to have the genetic test. His employer is unaware of his family history.

Dilemmas:

1. Do employers in industries involving public safety have the right to demand family health history information and/or use predictive testing for conditions that may impact on public safety about an individual whose current health status is excellent?

2. Who actually `owns' this information and who should decide who can access it?

3. Should individuals with a family history of diseases such as HD be required to undergo predictive testing before having children?

Case Study #3: **GP**

A General Practitioner (GP) has three male patients. Peter and Karl are aged eight years. Both are short for their age. Peter's short stature is due to a congenital deficiency in human growth hormone. His parents are both over 170 cm (5'7") tall. Karl, however, is simply short because his parents are both under 165 cm (5'5") in height. He has normal growth hormone levels.

A pharmaceutical company has used genetic technology to produce human growth hormone. It is an expensive treatment but is being used by many doctors to treat growth problems. Both Peter and Karl's parents want the GP to prescribe it for their sons.

A child's genetic height potential is determined by the genes inherited from both parents as well as by environmental factors such as diet. Therefore the treatment should enable Peter to reach a height similar to that of his parents and attain a normal stature. Karl's potential height is likely to be similar to his parents, that is, on the short side of normal. He will grow taller with the treatment, but will always be on the short end of the normal range for height.

The GP's third patient is Tom, an athlete aged 21. Tom aspires to the 2016 Olympic Games rowing team. Tom has also asked to be treated with human growth hormone. He believes that with the extra muscle bulk and strength that the treatment will give him, he may be able to achieve his Olympic ambitions.

Dilemmas:

1. Which of these three people should be entitled to use the genetically engineered product?

2. Will the use of genetically engineered products such as human growth hormone alter social perceptions and acceptability of characteristics like height?

3. The ability to create identical copies of a gene (cloning genes) in the laboratory is seen as an essential step in the ultimate treatment of genetic conditions – correction of a faulty gene (gene therapy). How much of a person's genetic information should be able to be cloned?

Case Study #4: **Ms. AP**

Ms AP, now 30 years old, has a rare genetic condition, affecting only about 25 people in Australia. In the course of the diagnosis of the condition, when she was a child, samples of skin and bone were taken for testing and subsequently stored in the pathology laboratory, as is common practice for such tissues. Consent for the tests was obtained from Ms. AP's parents. At that time it was not envisaged that these stored samples could be a source of DNA.

Research on the condition has been undertaken over the last five years and DNA has been extracted from the stored samples of skin and bone. Consent was not sought from Ms. AP, or her parents, to conduct research on the samples and on the extracted DNA. The research results in the discovery of an important gene and the gene is patented, providing the researcher and the Institution where the research was undertaken, with considerable funding for on-going work.

Dilemmas:

1. Who has ownership of the stored sample, and the DNA extracted from it?

2. Given the rarity of the condition, does Ms AP have the right to refuse consent for the research on her DNA? That is, how should the balance be struck between individual rights and public health in this case?

3. In the case of a child, a person not legally competent to act, or a deceased person, whose consent (if any) should be required for research, eg a guardian or next of kin?

4. Should the contribution of individuals or families, who have enabled research by contributing DNA samples, be acknowledged or reimbursed perhaps by some form of royalty?