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Ethics and Genetic Capability

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OBJECTIVES To develop in each student an understanding of the ethical issues surrounding the information emerging from genetic research and the developing concerns for fairness in the use of this new genetic knowledge.

Our increased genetic capability over the last thirty years has raised many ethical concerns. Many new discoveries of gene structure and function have come either directly or indirectly from the Human Genome Project. This project was conceived and implemented in the 1980's as an attempt to map the entire human genome, and as a result many new genes and alleles of genes have been discovered (Kevles and Hood, 1992; Suzuki and Knudtson, 1990). We are still trying to understand and interpret all of this new information. Unfortunately, because we do not always do this wisely or fairly, some complex ethical issues arise and need addressing. This was realized and commented on as early as 1990 (Hall, 1990).

The biggest problem seems to be that we try to apply knowledge before we fully grasp the details of what we have learned (Suzuki and Knudtson, 1990). The detection of a gene, once described and worked out, is often more accurate than our knowledge of how the gene functions. Thus we find people denied jobs simply because they carry a particular allele, such as the allele for Huntington disease, hemophilia or breast cancer. The allele may be present only in the heterozygous condition, and the job applicant turned down for "intermediate deficiency" of that gene without determining if the actual condition can or will occur. (Suzuki and Knudtson, 1990) Important ethical issues arise from the ability to screen for particular alleles, without fully understanding the implications of the presence of the allele (Beardsley. 1996). For example, may an individual be forced to provide a blood sample as a condition for employment? If the sample is requested in order to test for drug use, may it also be used as a screening device for genetic defects?

Another ethical problem arises with the recent ability to determine many of the characteristics of the fetus, including gender and possible genetic disorders. We can now also quite accurately use DNA sequencing or "fingerprinting" for positive identification of individuals forensically and in cases of disputed parental identity. These increased capabilities have generated the ethical issue involving the termination of pregnancy: Has a genetic disorder been detected? What genetic disorder, one that is life-shortening and painful such as Tay-Sach's disease? Is the fetus of an unwanted gender? Or is the termination for the convenience of the parents? Termination of pregnancy is induced abortion, which is probably the most generally debated ethical issue of our time in society.

Another concern is the right of self-incrimination: May an individual be forced to provide his own blood to the government for testing in criminal or civil cases, or for any other use? Or does this contradict the right against self-incrimination? So far, as in the O. J. Simpson case, it seems as if the suspect is required to provide a blood sample, as an extension of the regular laws regarding fingerprints. What are the victim's rights in cases involving blood evidence?

What is happening to the concept of physician-patient confidentiality? Who should have access to the results of blood tests? (Gorman, 1996). Should an adult automatically be told by their physician that they have a detected genetic disorder? What about Huntington disease, which usually does not show symptoms until a person is well into child-bearing age and may already have produced children? Some people who had parents with Huntington disease do not wish to be told if they carry the allele for this disorder (Wexler, 1990).

We must also be concerned with the question of individual rights as we grow increasingly more proficient in the use of genetic technologies. In the near future, will a perspective employee be required to submit a blood sample? What happens to a person who is carrying the genes for a genetic disorder? Is this legitimate grounds for denying employment and/or health insurance? May a person be denied coverage or suspended from a health plan if there is DNA evidence of a genetic disorder? Is carrying the gene for a genetic disorder really a "pre-existing condition" as is claimed by some insurance companies? Or is it really only the potential for a condition? Will the future see an attempt to breed out of the population deleterious genes? Will forced sterilization for "genetically inferior" individuals become the law of the land? These are all questions that have been raised in one context or another as parts of some serious attempts to influence the genetic composition of society. (Kevles, 1986; Herrnstein and Murray, 1994; Gould, 1981, 1995; Suzuki and Knudtson, 1990; Reilly, 1991).

"Wait a minute!" you say. "These are all rather fanciful examples. They could not really happen!" But most of these examples have already occurred. Several women already have been discriminated against by insurance companies and HMO's because of possible breast cancer (Beardsley, 1996; Smith, 1996). Medical files that used to be confidential between a physician and patient are becoming increasingly available to employers and insurance companies through access by computer (Gorman, 1996). A bill currently is being debated in Congress that would restrict immigration based, in part, upon IQ. One of this bill's major references is the book by Herrnstein and Murray (1994) that expounds the cause of racial differences in IQ.

The other day I saw a sign at a large discount store announcing that they conducted random tests for drugs, and drug users should not bother applying for a job. Usually the tests are simple urine tests, but if the company has a blood sample they are testing for drugs, what else might they test for without informing the employee? Recently two marines were court-martialed for refusing to donate blood and tissue samples. (Anon, 1996) Their reason for refusing was simply that they could not be sure how these samples would be used in the future. (Gorman, 1996).

There was a well-intentioned screening campaign for sickle-cell anemia developed during the early 1970's. But the situation soon "turned ugly". "Perfectly healthy carriers of the trait were led to believe that they were sick". Soon some states had defined the heterozygous condition as a disease. Some insurance companies began to deny coverage to heterozygotes on the grounds that "they had a pre-existing medical condition". These people were also denied jobs in certain fields. The ultimate solution suggested by scientists was that these heterozygous people forgo having children—an idea that was quickly interpreted by the black community as a form of racial genocide. (Rennie, 1994).

Attempts to use genetic information medically frequently involve intentional alterations in an organism's

genetic composition. Unfortunately, we do not always know what the results of our attempts at genetic engineering will be. Unexpected results in the future may cause problems that we have not anticipated or cannot even imagine. Consider the following example. In one case, mice were manipulated in a genetic recombinant experiment by “knocking out” a gene essential for the synthesis of nitric oxide, a neurotransmitter in the brains of mice (and also of men). Attempts to block production of this neurotransmitter resulted in producing some very ferocious male mice, (females were not affected), whose behavior was six times more aggressive than normal mice. These males also engaged in excessive and inappropriate sexual advances to females, in what can only be described as rape. (Toufexis, 1995).

A similar experiment on mice, involving the enzyme monoamine oxidase A, led to similar results. Here the young male mice that were deficient in the enzyme showed extremely aggressive behavior and other signs of neural abnormalities. They constantly clasped their female litter-mates. (Hilchey, 1995) The implication of both of these reports is that similar conditions exist in humans and that these enzyme deficiencies are responsible for these types of aggressive behavior. There are known rare, abnormally aggressive human males who lack normal amounts of MAOA. It is suggested that a drug therapy can be developed to treat these individuals.

Is it fair to raise or lower people’s hopes with reports of new gene locations and structures, and of new gene therapies? It seems every week there is another report of some new gene elucidated or of some new gene therapy in the news. Recently there have been reports of a genetic test for the breast cancer gene (Beardsley, 1996a) and a gene therapy for baldness (Hilchey, 1995a).

There have been many other reports of attempts at gene therapy. The attempt to correct cystic fibrosis by inserting the correct gene with a viral inhalation spray has probably obtained the most publicity. But the fact remains that gene therapy has so far not been successful. And every time we publish another account of a gene or a gene therapy we raise the hope for a cure in those afflicted individuals.

The gene therapy field is dominated by commercial companies that develop and market these therapies (including companies in biotechnology, drugs, agriculture, diagnostic laboratories and even HMO’s). Many of these companies seem more interested in their profit margin than in the efficacy of their gene therapies (Kolata, 1995b). To date there has only been one instance where gene therapy has been successful. This was an attempt to insert the correct gene for adenosine deaminase into white blood cells. The result was the restoration of the immune system (Anderson, 1995). And from time to time the patient must still return for booster treatments.

But there has also been a recent report of a genetic cure for baldness (Hilchey, 1995a), which stated that liposomes with the correct gene had been shot into the skin of hairless mice. The liposomes then gave up the correct genes to follicular cells and hair growth was restored to a near-normal condition. Great news for balding people! Except that the experiment was conducted using mice and the last paragraph of the article stated that mouse skin absorbs liposomes much more easily than human skin. Again are we raising false hopes?

In a more imaginative vein, there are also reports of DNA being used in the future as a computer (Kolata, 1995a) and a recent report on redefining the gene for femaleness (Angier, 1994). There is also another report on the identification of the gene for dysautonomia. This work was funded by a small foundation made up of the parents of children afflicted with the disease, parents who desperately wish for some progress on an affliction which is seriously impacting the lives of these families (Kolata, 1996).

Below I have included in Table I a list of gene therapies undergoing clinical trials in 1995. Just one year later, this list would seem to be woefully out-of-date. But it gives a good idea of the breath of areas and scope of research going into gene therapy. (Anderson, 1995).

Table I. Diseases Being Treated In Gene Therapy Trials (Anderson, 1995)

¥ Cancer (Including melanoma, renal cell, ovarian, neuroblastoma, brain, head and neck, lung, liver, breast, colon, prostate, mesothelioma, leukemia, lymphoma, multiple myeloma)
¥ Severe combined immunodeficiency (SCID)
¥ Cystic Fibrosis
¥ Gaucher's Disease
¥ Familial Hypercholesterolemia
¥ Hemophilia
¥ Purine nucleoside phosphorylase deficiency
¥ Alpha-1 antitrypsin deficiency
¥ Fanconi's anemia
¥ Hunter's syndrome
¥ Chronic granulomatosis disease
¥ Rheumatoid arthritis
¥ Peripheral vascular disease
¥ AIDS

Another ethical problem involves changing the cells of the germ line (stem cells which divide to produce sperm cells). It is one thing to change somatic cells in a patient's body. The result is confined to that one individual. But when the germ line cells are changed all subsequent offspring will show the effect. Stem cells of mice have recently been successfully changed (Kolata, 1994). But since we are not entirely sure of the effects of changing germ line cells, there are grave doubts being raised over these experiments (Kolata, 1994a). Might changes in human germ line cells be used to attempt to breed a "super race" of men? This harks back to experiments performed in Nazi Germany. Will future prospective parents seek "designer sperm

cells”? If this technique of changing germ line stem cells can be extended to humans, it raises some very basic ethical questions.

It is easier to genetically change plants and microbial organisms than it is to alter the genetic composition of mammals. But here again ethical questions are raised. A plant has recently been genetically engineered to take up mercury from the environment (anon., 1996a). But this has only been accomplished in the laboratory and we do not know the effects of releasing this altered genome into the environment. The effect might be one entirely unexpected.

In one carefully controlled experiment, oilseed plants were genetically engineered with a gene for resistance to an herbicide. These plants were then allowed to grow with a native related plant, a weed called wild mustard. The result was that there was hybridization and the weed ended up with the gene for resistance to the herbicide. In this case the experiment was closely controlled, all the plants were destroyed and there was no harm done (Beardsley, 1996). However, this experiment does show how easily genes can escape from genetically engineered crops into the surrounding natural environment.

The Bt gene is a gene found in a bacterium that codes for the production of a protein that is a natural insecticide. This gene has recently been engineered into corn, cotton and potatoes. This would mean that we could have plants with a built-in insecticides, and this would greatly reduce the use of harmful chemical insecticides in the environment. But very quickly two very disturbing problems seem to be arising. One, will insects develop a tolerance for this protein? This seems to have occurred in some trials of engineered cotton in Texas. And two, will the Bt gene “escape” into the wild, weedy relatives living in the area? If this happens will they have an advantage over native plants in that the weeds will be more resistant to insects? (Feder, 1996). Again, it seems as if we are not sure of what we are attempting.

In another experiment, a gene from Brazil nuts was introduced into soybeans intended for use as animal feed in an attempt to boost the methionine level in the soybeans. But the introduction of new genes leads to the production of new proteins. In this case one of the new proteins caused a “life-threatening allergic reaction in people”. The company quickly stopped the project (Beardsley, 1996). But here again we see an unexpected result from a genetic engineering.

There have been several incidents in the past few years of people becoming sick, and some actually dying, from hemorrhagic colitis. This disease is a severe form of diarrhea and is caused by the *Escherichia coli* bacterium, strain O 157: H7. But *E. coli* is common and normally present in large numbers in the intestinal tract of mammals. What caused this strain to become so virulent?

There is another bacterium named *Shigella dysenteriae* . This bacterium produces Shiga toxin which causes diarrhea. The gene for Shiga toxin has jumped from *Shigella* to *E. coli.* When present in the much more common *E. coli* the Shiga toxin gene causes the production of the Shiga toxin in large quantities. If undercooked meat, especially ground hamburg with its large internal surface area, is eaten the *E.coli* in the hamburg ends up in the intestine. If it is carrying the gene for Shiga toxin, hemorrhagic colitis will result (Hilts, 1996).

This seems to be a case of natural genetic engineering. But the consequences for man have been severe. Many people have been stricken with hemorrhagic colitis and a few have died. Remember the Jack-In-The-Box incident of 1993? Four children died and many people were stricken. In July, 1996 the same strain of *E. coli* caused extensive food poisoning in Japan, with at least four deaths reported (Anon., 1996b). A later report sets the death toll at 100 and the number stricken at 8700. It was reported that there are 100 new cases per day

(Anon, 1996c)

One of the genes in humans that has been identified is the apo E gene. There are four alleles for this gene and an individual inherits one allele from each parent. People with two copies of the apo E4 allele have an increased risk for heart attack of from 30% to 50%. Thus physicians are increasingly including identification of this gene in blood work for heart patients. However, apo E4 is also an indicator for Alzheimer's disease. If a person has two copies of the apo E4 allele there is a 90% chance of developing Alzheimer's disease by the age of eighty (Kolata, 1995).

And thus is posed another serious ethical dilemma. If a physician tests for apo E and finds two copies of apo E4 what does he or she do? Do you tell an otherwise normal 50 year old patient that they have a 90% chance of developing Alzheimer's disease by the age of eighty? Should you tell someone that in all probability they will develop a degenerative brain disease for which medical science has not yet developed the ability to alter or slow the course of the degeneration? We are becoming very adept at identifying genes and linking them to disorders, but we can't always treat the disorder. Should the physician simply remain silent until the onset of the degenerative process? Does knowing that you carry two copies of the apo E4 allele cause stress? And can this stress contribute to the onset of Alzheimer's disease? There are many facets to this ethical problem.

One other area where gene identification has been used is in an attempt to predict behavior. Several years ago it was suggested that a large proportion of those males with an extra Y chromosome (the XYY condition) were in prison for violent crimes (Kevles, 1985). Thus the extra Y become known as the "criminal chromosome". Subsequent work showed this analysis to be completely spurious. There is no basis in fact for asserting that an XYY male is prone to violence and crime. And yet this idea seems to persist in our culture (Gibbs, 1995). Other behavioral studies, especially the study of monozygotic twins done at the University of Minnesota, have shown "a strong genetic contribution" to many traits including religiosity, political persuasion, leisure-time interests, sexual preference, intelligence, personality types and other traits. But the Minnesota study seems highly flawed by its selection method (Horgan, 1993).

The point is this. If behavioral traits are genetic, then we are possibly in a position to identify the genes involved. And if we identify these genes we may contemplate eliminating the undesirable genes from the population. But who decides which genes are undesirable?

We already know that there are some links between "brain chemistry, heredity, hormones, physiology and assaultive behavior" (Gibbs, 1995; Blakeslee, 1996a). For example, physically aggressive men have higher levels of testosterone. Also—seratonin has a calming effect on the brain. Men with low levels of seratonin are inclined to impulsive aggression. See the discussion above concerning MAOA (Hilchey, 1995). However, these studies are merely suggestive of what is happening in the brain. There is still much work to be done to definitely link physiology to antisocial behavior.

While these studies are as yet preliminary and tentative, this fact has not stopped other people from suggesting that people with an extra Y chromosome or with low levels of MAOA be treated as potential criminals. They even went so far in Boston as to begin screening new-born babies for the XYY condition. This was stopped when subsequent studies failed to find a correlation with aggression (Gibbs, 1995). However, the potential is there for a eugenics program that might have severe consequences in society in the near future. (Kevles, 1985)

The ethical considerations of all of these examples and possibilities are enormous. And these are considerations that all students need to be aware of, for in the near future we will, as a society, be asked to

decide on the limits of many of these new genetic procedures. Several ethical issues that we have considered here are:

1. Is it fair to raise or lower people's hopes?
2. Is it ethical to change the germ cell line?
3. Are we releasing genes unwittingly into the environment?
4. Are we rushing to judgment before we fully understand the implications of what we have discovered?
5. Are we violating an individual's legal rights as well as their right-to-know and their right to privacy/confidentiality?

PRACTICUM

STRATEGIES Students will learn by role-playing. This unit consists of
four situations in which the students may become involved in

determining the outcome of issues which are based on genetics.

These four situations are:

1. A suit brought by a couple against a physician because they were not given proper genetic counseling and subsequently had a child with Down's syndrome.
2. A thirty year old person fired from her job because her genetic profile, which showed that she was carrying the gene for Huntington disease, became available to her employer.
3. A young woman is found to be carrying the BRCA1 gene. Her request for payment for a prophylactic mastectomy is rejected by her insurance company. Shortly after she is fired and her medical insurance is terminated.
4. A proposed law in 2010 requires sterilization of anyone whose IQ score is less than 70.

BACKGROUNDS
Situation #1: Down's syndrome is a genetic disorder resulting from aneuploidy, the presence of an extra

chromosome 21. This extra chromosome results from a non-disjunction during the production of a human ovum. Sometimes the extra portion of chromosome 21 may be translocated to chromosome 15. The symptoms of this syndrome include characteristic facial features, a flattening of the face, lack of development of the nasal area, and the characteristic eye shape—similar to the almond-shaped eye of oriental people. Other symptoms include heart defects, an increased susceptibility to respiratory infections, short stature and mental retardation. The tongue is enlarged and flat and this makes speech difficult. The life span is also much shorter than normal, with 50% of the afflicted children dying by the age of five. As a woman gets older, the chances of having a child with Down's syndrome increases. Table II below clearly shows this increase (Stirling, 1996)

TABLE II. Down's Syndrome Inheritance

Mother's Age	Incidence of Down's Syndrome
16-26	1:1300
27-34	1:700
35-39	1:350
40-44	1:100
45-47	1:30
48 + above	1:12

In this case the couple had waited until the woman was 35 to start their family. They were told that there was an increased chance that there might be birth defects in their child, but were given no specific information on Down's syndrome. There was some informal discussion of birth defects and amniocentesis, but no formal counseling. They belonged to an HMO in California which does not allow for this type of counseling.

Situation #2: Huntington disease is a genetic disorder which is caused by a lethal dominant allele located on the short arm of chromosome 4 (Wexler, 1995). At about 35 to 40 years of age, the afflicted individual begins to suffer a deterioration of the nervous system. The results are always irreversible and fatal. Mental capacity usually diminishes and is gone in five to ten years, but the individual may survive in a vegetative state for many more years. Most people so afflicted are able to start a family well before the onset of the affliction.

In the present case, the young woman had worked for a company for twelve years. Her father had died of Huntington disease several years ago. She finally decided that she wanted to know if she would also have her life shortened by this disorder. At thirty, she thought she might like to do some things and make some plans. Her blood test was positive. Her employer requested her medical file from her physician, producing a medical release that she had signed when she began work at the company. She had no knowledge of this form. Shortly thereafter she was terminated for "unacceptable work performance". This after twelve years with the same company, and many positive evaluations in her file.

Situation #3: The BRCA1 gene codes for a protein. This protein is packaged and excreted from the cell. It is partly broken down by an enzyme into large polypeptides, which act as messenger molecules. These molecules are accepted at receptor sites on cells of mammary and ovarian tissue. BRCA1 seems to act as a regulator of cell division and prevents too-rapid cell division of these tissues. When the BRCA1 gene is mutated it can no longer produce this messenger molecule. Cell division is then not properly regulated and rapid cell division and a tumor are the result. (Angier, 1996)

The BRCA1 gene was discovered in 1994 and a test for its detection has recently been patented by the Myriad Genetics Corporation. They plan to offer this test commercially by the end of 1996. It is presently available only in research settings in medical schools and hospitals. (Beardsley, 1996)

Those families with hereditary breast cancer account for less than ten percent of all cases. But mutation of the BRCA1 gene confers an 85% lifetime risk of breast cancer. Further complicating the picture is the recent identification of a second breast cancer gene BRCA2.

In the present case, the young woman requested genetic screening for the BRCA1 gene, since both her mother and aunt were afflicted with breast cancer. The results were positive for a mutated BRCA1 gene. When she asked her insurance company about paying for a prophylactic mastectomy under her employer's group health plan, she was told that they would not cover the procedure since she did not have breast cancer. Shortly thereafter she was fired by her employer and her medical insurance was terminated. She had worked for this company as an accountant for seven years and her work record was excellent.

Situation #4: Enforced sterilization is not a new phenomenon. It has occurred in many countries at various times in attempts to "weed out" people with mental deficiencies. The policies and practices of Nazi Germany are a good example. Even in the United States enforced sterilization has been practiced (Reilly, 1991; Kevles, 1985). In the 1930's eugenics was in fashion. Illiterate black women were declared mentally retarded because they could not read and were subsequently sterilized. The assumption was that this "mental retardation" was genetic and inherited. "By 1931, 27 states had passed laws allowing compulsory sterilization of 'the feeble-minded,' the insane and the habitually criminal." (Gibbs, 1995)

At the present time there are suggestions that the U.S. deny immigration to individuals who do not "pass" an IQ test. The Senate of the U.S. has recently heard this and other arguments in support of a more restrictive immigration policy. (Reilly, 1991; Herrnstein and Murray, 1994; Jensen, 1969; Gould, 1981, 1994)

This situation is based upon the premise that Scientific Racism is on the rise again. There are four recent books that point to this phenomenon—Herrnstein and Murray (1994), Rushton (1995), Brimelow (1995) and D'souza (1995). This situation is an extrapolation based upon what I have seen and read in recent years and is a "worst-case scenario". Yet I do not feel that it is beyond the realm of possibility. For a superb treatment of the history and present state of eugenics read the book by Kevles (1985).

PROCEDURES

For each of these situations, the students are assigned roles and directed to the relevant literature in order to understand and defend their particular position. Each student's role is critical. Without adequate research and development by the students, the situations will not develop in a meaningful way when acted out. Key roles must go to students capable of reading and understanding the background and preparing their positions. Yet at the same time, no one may be excluded or minimized in their role. Obviously all roles are not of equal importance but students must feel what they are doing is of importance or they will not perform in a meaningful fashion.

More literature is available in the teacher's bibliography. Teachers must master not only the genetics of each case, but the ethical issues involved. And ethical issues never seem to have neat answers. There will be outlines and schemes presented which will help the teacher in preparing the students for their presentations.

Some of the scenarios are set in the near future. There will also be some materials presented from which the teacher and class may be able to imagine what our world will be like in fifteen to fifty years.

EDUCATIONAL OUTCOMES

Student will learn:

1. To do a literature search and extract information from published materials.
2. To present forceful and factual arguments defending their positions, based upon their literature research.
3. To understand something of this country's legal and legislative systems by assuming both legislative and judicial roles in the classroom presentations of these ethical arguments.
4. To realize that there are various points of view; that ethical standards among different races, religions and political groups do not always coincide; that ethics boils down to a respect for privacy and the beliefs of others; and to realize that dogmatism will not bring solutions.

SCENARIOS

SITUATION ONE: A suit brought by a couple against a physician because they were not given proper genetic counseling and subsequently had a child with Down's syndrome.

ROLES

MOTHER OF DOWN'S SYNDROME CHILD

HUSBAND OF MOTHER/ FATHER OF CHILD

RESPONSIBLE PHYSICIAN

HMO REPRESENTATIVE

LAWYER FOR PLAINTIFFS

LAWYER FOR DEFENDANT

WITNESSES CALLED BY EACH SIDE (Number Varies)

JUDGE

JURY OF TWELVE CITIZENS

COURT PERSONNEL AS NEEDED TO CREATE A ROLE FOR EACH STUDENT

SOURCES

Campbell, 1993

Hoffman, D'Amado and Seeger, 1988

Suzuki and Knudtson, 1990

Kevles and Hood, 1992

Stirling, 1996Wertz and Fletcher, 1989

SITUATION TWO: A thirty year old person fired from her job because her genetic profile, which showed that she was carrying the gene for Huntington disease, became available to her employer under questionable circumstances

ROLES
WOMAN FIRED FROM HER JOB

PRESIDENT OF COMPANY INVOLVED

LAWYER FOR PLAINTIFFS

LAWYER FOR DEFENDANT

WITNESSES CALLED BY EACH SIDE (Number Varies)

JUDGE

JURY OF TWELVE CITIZENS

COURT PERSONNEL AS NEEDED TO CREATE A ROLE FOR EACH STUDENT

SOURCES
Campbell, 1990Anon., 1996

Suzuki and Knudtson, 1990Bok, 1978

Kevles and Hood, 1992Gorman, 1996

Kevles, 1986Kolata, 1995

Wertz and Fletcher, 1988Wexler, 1995

Beardsley, 1996

Hoffman, D’Amado and Seeger, 1988

SITUATION THREE: A young woman is found to be carrying the

BRCA1 gene. Her request for payment for a prophylactic mastectomy is rejected by her insurance company. Shortly after she is fired and her medical insurance is terminated.

ROLES

YOUNG WOMAN WHO IS FIRED
PRESIDENT OF COMPANY INVOLVED
LAWYER FOR PLAINTIFFS

LAWYERS FOR DEFENDANT (SEVERAL)
WITNESSES CALLED BY EACH SIDE (Number Varies)
JUDGE
JURY OF TWELVE CITIZENS
COURT PERSONNEL AS NEEDED TO CREATE A ROLE FOR EACH STUDENT

SOURCES

Campbell, 1993Angier, 1996

Suzuki and Knudtson, 1990Bok, 1978

Beardsley, 1996Gorman, 1996

Kevles and Hood, 1992Smith, 1996

Wertz & Fletcher, 1989

Hoffman, D'Amado and Seeger, 1988

SITUATION FOUR: A proposed law in 2010 requires sterilization of anyone whose IQ score is less than 70.

ROLES

MODERATOR OF THE LEGISLATIVE BODY
PROPONENTS FOR THE BILL IN QUESTION
OPPONENTS OF THE PROPOSED LEGISLATION
EXPERT WITNESSES CALLED BY EACH SIDE (Number Varies)

SOURCES

Campbell, 1993Gorman, 1996

Suzuki and Knudtson, 1990 Horgan, 1993

Herrnstein and Murray, 1994Kevles, 1985

Kevles and Hood, 1992Gould, 1981

Jensen, 1969Gould, 1994

Reilly, 1991

Hoffman, D'Amado and Seeger, 1988

STUDENT ROLES: EXPLANATION AND HELPFUL IDEAS

You, the students, will determine the success or failure of this assignment. If you are assigned an active role, such as a lawyer or witness, you must each read several books and articles and pull all of this information together.

JURY MEMBERS, you must listen to the information presented and then come to a decision based upon that information. You may not use outside information or opinions of your own. You must try to render a fair and impartial verdict based solely upon the evidence presented.

LAWYERS, you may know that you are right. Justice is on your side! But remember, Justice is blind. No matter how sure you are of your position, you must convince a jury of your surety, and convince them that you represent the valid and successful side of the dispute. You must be able to present credible expert witnesses, and be able to question the credibility of your opponent's expert witnesses.

The only way for you to win is to thoroughly understand the case you are arguing. You must read and understand all of the background material. If you do not understand the case, you cannot win for your client. And you can be sure that your opponent lawyer will have done the necessary homework!

WITNESSES. Lawyers may assign fellow students as expert witnesses. These expert witnesses must also thoroughly research and understand the background material, relevant to their position or occupation. All witnesses must be advised to only contribute what you as a witness would have knowledge of. Do not try to be helpful by volunteering information that you have discovered, but that you in the role of a witness would not have. Witnesses should include laboratory representatives, DNA specialists, medical geneticists and any other roles that the lawyers think would be helpful to their case.

JUDGES must be responsible for a fair trial. You are not expected to have read a tremendous amount of background material. It must be sufficient for you to understand what is being talked about in court. You are expected to make sure that the trial is carried out in a civil manner, and that what is said is fair and accurate in terms of law. You will need to do some research on court procedures and the legal background of similar cases. You may also have to rule on testimony of witnesses and whether or not they would have knowledge about the subject upon which they are testifying. (Blakeslee, 1996)

TEACHERS: SOME ADDED NOTES

1. It is intended that only one scenario be attempted by each group of students. If the class is small, this might mean that only one scenario would be attempted. These scenarios will all require at least twenty people.You might try using only six students for the jury.
2. This paper is being written during the summer of 1996. By the time you read it and decide to use it, there will probably be a large number of additional source articles to present to the

students.
3. Some of the scenarios may be moot points by the time you are ready to use them. For example, situation three involves a young woman and her insurance company. Governor Whitman of New Jersey in July of 1996 signed into law a bill making it illegal for insurance companies to have access to genetic testing results.
4. There should be some sort of introductory class discussion and analysis of the ethics and morality involving genetic information and its accuracy, accessibility, confidentiality and dissemination. There also needs to be a discussion about possible differences in the ethical positions taken by geneticists and physicians, not to mention insurance companies, pharmaceutical companies, HMO's, and businesses. The entire concept of honesty and trust in government and companies might be examined (Bok, 1978).
5. I have included in table III a scheme for assessment of student performance. This is based in part upon the CAPT science experiment assessment, and partly upon a scheme from Stephen Beasley-Murray, whose paper appears in this same series.

Table III: Assessment of Student Performance

STUDENT: ROLE:
DIMENSION SCORE
Information

¥ Information presented was accurate and understandable 3

¥ Information presented was essentially correct 2

¥ Information was lacking in detail and clarity 1

¥ Information was inaccurate and unclear 0

Effectiveness

¥ Statements made were concise and informative 3

¥ Statements made were adequate 2

¥ Statements made were poor 1

¥ Statements made did not address the issue 0

Argument/Testimony

¥ Was relevant and pertinent to the issue 3

¥ Was mostly relevant 2

¥ Was somewhat irrelevant 1

¥ Was irrelevant or missing 0

Conclusions

¥ Were valid, relevant and clearly expressed 3

¥ Were generally valid and fairly clear 2

¥ Were not entirely valid and not entirely clear 1

¥ Were invalid, irrelevant or missing 0

Total

COMMENTS:

Teacher's and Student's Bibliography

Anderson, W. French. 1995. "Gene Therapy" Scientific American Vol 273: 124-128 Sept.

"Several hundred patients have already received treatment. In the next century the procedure will be commonplace". A good synopsis of progress to date and some interesting thoughts about the next century.

Angier, Natalie. 1994. "Biologists Hot on Track Of Gene for Femaleness" *New York Times* , Tuesday, Aug. 30, pg C1

A good report on the issue of gender determination in the developing fetus, and how a new concept of gene control of gender is emerging.

Angier, Natalie. 1996. "Surprising Role Found for Breast Cancer Gene" *New York Times* , Tuesday, March 5, pg C1

A good article about the BRCA1 gene and its functions. A possible solution to the problem of breast cancer treatment.

Anon. 1996. "2 Marines who refused DNA test face court-martial" *The Providence (R.I.) Sunday Journal* April 14, pg A17

A brief report of two marines who were court-martialed for refusing to donate blood and tissue. They were worried about how their genetic data might be used.

Anon. 1996a. "After Genetic Engineering, a Weed Gobbles Up Mercury" *The New York Times* Tuesday, April 16,

pg C4

A report of a laboratory experiment in which a genetically engineered plant absorbed and neutralized large amounts of mercury

Anon. 1996b. “Toll Rising, Japan Warns Against Eating Raw Meat” *New York Times,* Tuesday, July 23 page C3

A short account of the outbreak of food poisoning in Japan caused by the Shiga toxin carried by *E. coli* . See also Anon. 1996c

Anon. 1996c. “Japan Turning to Use of Antibiotics” *Providence (R.I.) Sunday Journal,* July 22, page A3

A second account of this outbreak of food poisoning. The count is 100 people dead and 8700 people sick. New cases are being reported at the rate of 100 per day. See also Anon. 1996b.

Beardsley, Tim. 1996. “Vital Data” *Scientific American* 274:100-105 (March)

A good recent article on some of the implications of genetic findings and the uses to which they have been applied. There is a good discussion of the BRCA1 gene.

Beardsley, Tim. 1996a. “Advantage: Nature” *Scientific American* 274: 33 (May)

Could escaped genes from bioengineered crops give weeds a crucial boost? Some weeds were shown to become immune to an herbicide by hybridizing with a crop plant

Blakeslee, Sandra. 1996. “Genetic Questions Are Sending Judges Back to Classroom” *The New York Times* Tuesday July 9, page C1

Judges are given a series of seminars to acquaint them with DNA techniques that they need to know in order to conduct a trial involving genetic evidence.

Blakeslee, Sandra. 1996a. “Researchers Track Down a Gene, May Govern Spatial Ability” *New York Times,* Tuesday, July 23 page C3

Another indication that at least portions of our cognitive ability are governed by genes. This is a good account of the discovery of one such gene.

Bok, Sissela. 1978. *Lying: Moral Choices in Public and Private Life* Pantheon Books, New York

A philosopher looks at lying in public and private life. Included are discussion of government, medicine, law, academia, journalism and in the family

Brimelow, Peter. 1995. *Alien Nation: common sense about immigration & Am. life* Random House, New York

Claims that we need immigration restrictions to restore the racial homogeneity of the white population. It is the same old racist material with scientific overtones.

Byne, William. 1994. “The Biological Evidence Challenged” *Scientific American* 270:50-55 May

A refutation of LeVay and Hamer’s article. Byne’s paper seems to have several strong arguments against a

strictly genetic cause for homosexuality

Campbell, Neil A. 1993. *Biology , Third Edition* Benjamin/Cummings Pub. Co Redwood City, Cal.

A standard college textbook with a good section on genetics. There is also good coverage of DNA structure and replication, as well as RNA, transcription, and protein synthesis.

D'Souza, Dinesh. 1995. *The End Of Racism: principles for a multiracial society* Free Press, New York

This book deals with an end to affirmative action. Racial definitions are assumed. It is the same old racist material with scientific overtones.

Feder, Barnaby J. 1996. "Geneticists Arm Corn Against Corn Borer, Pest May Still Win" *New York Times,* Tuesday, July 23 page C1

A good account of an attempt to arm a crop plant with a built-in fertilizer and the possible consequences. There is a good discussion of both effects on the target insects and the environment.

Gibbs, W. Wayt. 1995. "Seeking the Criminal Element" *Scientific American* Vol 272: 101-107 (March)

"Scientists are homing in on social and biological risk factors that they believe predispose individuals to criminal behavior. The knowledge could be ripe with promise—or rife with danger."

Gorman, Christine. 1996. "Who's Looking at Your Files?" *TIME Magazine* May 6, pages 60-62

A frightening article explaining just how easy it is to obtain a computer file of confidential medical records. This article cuts right to the heart of the issue of genetic confidentiality.

Gould, Stephen Jay. 1981. *The Mismeasure of Man* W. H. Norton Co., New York

The book that refutes claims of racial superiority, especially those claims based on the notion of IQ differences in races. A very thorough argument against the idea of racial differences in intelligence.

Gould, Steven Jay. 1994. "Curveball" in *New Yorker* , New York Nov. 28, 1994 pgs 139-150

A devastating refutation of Murray's book *The Bell Curve* . This article is mainly concerned with statistics, and a good one to read to learn how statistics may be manipulated and misrepresented.

Hall, Stephen S. 1990. "James Watson and the search for biology's 'Holy Grail" *Smithsonian* 20:41-49 Feb.

An article on the start of the HGP and a discussion of some of the early concerns that were raised over the consequences of this project.

Herrnstein, Rich. J. & Charles Murray. 1994. *The Bell Curve: Intelligence and Class Structure in American Life* The Free Press, New York

The book that seriously suggests that there are racial differences in IQ's. The authors go on to suggest that eugenic measures need to be taken to remove some genes from the population.

Hilchey, Tim. 1995. "Enzyme Gap Makes Mice Violent" *The New York Times* Tuesday, June 27, pg C3

"A study may shed new light on human aggression" This paper reports results of a study of the MAO gene in mice and the effects on the brain.

Hilchey, Tim. 1995a. "Gene Gun Could Treat Hair Loss" *The New York Times* Tuesday, July 11, pg C3

"Waking up follicles factories with a biotechnical barrage" by the use of genes in liposomes is the subject of this report. What has happened since?

Hilts, Philip J. 1996. "Gene Jumps To Spread A Toxin In Meat" *The New York Times* Tuesday, April 23, pg C1-3

A vivid example of natural genetic engineering with deadly results for humans. The gene that produces Shiga toxin is now in the common intestinal bacterium *E. coli* .

Hoffman, D'Amado & Seeger, eds. 1988. *Embryos, Ethics and Woman's Rights: Expl. New Repro.Tech.* Harrington Park Press, New York and London

A thoughtful symposium exploring ethical issues surrounding reproductive technology. There are several papers that discuss gene therapy and manipulation. Also some interesting feminist papers on reproduction.

Horgan, John. 1993. "Eugenics revisited" Scientific American June, Vol 268: 122-131

An account of some eugenic concerns being raised by new genetic information. Included is a discussion of XYY chromosomes and of aggressive males.

Jensen, Arthur. 1969. "How much can we boost IQ and scholastic achievement?" *Harvard Educational Review* 33:159-179

An older paper on IQ and society. It again links intelligence w to race. Probably most interesting for its historical significance

Kevles, D. J. and L. Hood, eds. 1992. *The Code of Codes* Harvard Univ. Press, Cambridge, Mass.

A somewhat more technical book than Suzuki's, its covers about the same ground. There are some very good sections on ethical concerns.

Kevles, Daniel J. 1985. *In the Name of Eugenics: Genetics and Uses of Human Heredity* Alfred A. Knopf, New York

An absolutely excellent book which thoroughly traces the development of eugenics and explains the current status of the subject. I cannot recommend this book too highly. It is excellent!

Kolata, Gina. 1994. "Gene Technique Can Shape Future Generations" *The New York Times* Tuesday, Nov 22, pg A1 & C1

Discussion of a report of a successful attempt to introduce genes into mouse stem cells. The ethical implications are discussed. (See also Kolata, 1994a)

Kolata, Gina. 1994a. "Ethicists Wary Over New Gene Technique's Consequences" *The New York Times* Tuesday, Nov 22, pg C1

A discussion of concerns over the genetic engineering of germ line stem cells. (See also Kolata, 1994). The main concern seems to be over what modified stem cells might be used for.

Kolata, Gina. 1995. “If Test Hints Alzheimer’s, Should a Patient Be Told?” *The New York Times* Tuesday, Oct. 24 pg 1 & C6

A very good discussion of the ethical dilemmas surrounding the apo E gene and Alzheimer’s disease. This gene is involved in both heart disease and Alzheimer’s disease.

Kolata, Gina. 1995a. “A Vat of DNA May Become Fast Computer Of The Future” *The New York Times* Tuesday, April 11, pg C1

An interesting report on an attempt to use DNA as a computer matrix.

Kolata, Gina. 1995b. “In the Rush Toward Gene Therapy, Some See a High Risk of Failure” *The New York Times* Tuesday, July 25, pg C3

An article questioning the motives of many companies in the gene therapy field. “The field is driven by nonmedical concerns, critics say.” Not a single patient has been helper by gene therapy.

Kolata, Gina. 1996. “Parents Take Charge, Putting Gene Hunt Onto the Fast Track” *New York Times,* Tuesday, July 16 page C1

An unusual account of a group of parents and their involvement in their children’s affliction. Implied here are some concerns about how genetic disorders are given priority.

LeVay, Simon and Dean H. Hamer. 1994. “Influence for a Biological Influence in Male Homosexuality” *Scientific American* 270:44-49 May

One of two articles debating homosexuality and genetics. But most of the evidence cited could also have a developmental origin. See also the paper by Byne (1994)

Reilly, Philip R. 1991. *The Surgical Solution: A History of Involuntary Sterilization in the U.S.* Johns Hopkins Univ. Press, Baltimore

A good and thorough discussion of why sterilization was acceptable and of how our ideas have changed with time. The emphasis is on why, with a clear discussion of the legal cases involved. The author is a lawyer and physician.

Rennie, John. 1994. “Grading the Gene Tests” *Scientific American* , June, Vol 270: 88-97

A good article which discusses the pros and cons of gene tests and discusses some of the problems involved with sorting out which tests are really reliable.

Rushton, J. Phillipe. 1995. *Race Evolution and Behavior* Transaction Publishers, New Brunswick, N. J.

Uses both the evolution and IQ arguments for maintaining that there are racial differences and that whites are superior to other races. It is the same old racist material with scientific overtones.

Smith, Martha. 1996. “Breast cancer gene raises job and privacy issues” Providence (RI) Sunday Journal July 7,

1996, page E8

A further account of some of of the problems involved with carrying the BRCA1 gene. The problem continues to be that our ability to detect far outdistances our ability to cure.

Stirling, J. 1996. “Chromosomes.” pgs 306-309 *Encyclopedia of Life Sciences,* Marshall Cavendish, New York

A basic account of chromosome structure, genes, chromosome number and recombination. Information on Down’s syndrome is included in a sidebar.

Suzuki, David & Peter Knudtson. 1990. *Genethics: The Ethics of Engineering Life, revised ed.* Harvard Univ. Press, Cambridge, Mass.

An excellent book that explains in plain language how genes are made, how they work, and the controversies surrounding the new genetic knowledge. This is the one to read.

Toufexis, Anastasia. 1995. “Monster Mice. Scientists breed rodents that rape and kill.” *TIME* 146: 76 Dec. 4

Unexpected results in a genetic recombinant experiment. Attempts to block production of a neurotransmitter resulted in suppression of a gene for nitric oxide production, producing some very ferocious mice.

Tyler, Patrick E. 1996. “Lacking Iodine in Their Diets, Millions in China Are Retarded” *The New York Times* pg A1 and A10, Tuesday, June 4

This article explains how entire villages ended up mentally retarded because of a lack of Iodine in their diet. But under some circumstances, these people might have been judged genetically defective.

Wertz, D. and J. G. Fletcher, eds. 1989. *Ethics and Human Genetics: A Cross-Cultural Perspective* Springer-Verlag, New York

An excellent book on ethics and medical genetics. Included are reports from 19 countries. The USA report is very detailed and there is an excellent general consideration as well.

Wexler, Alice. 1995. *Mapping Fate: a memoir of family risk, and genetic research* Times Books, New York

A personal account of a family’s dealing with Huntington Disease. Alice is the sister of Nancy who contributed so much to our understanding of this disorder.