CASE STUDY:
Genetic Testing vs. Individual Privacy

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BACKGROUND:

This case study, involves a look at the debilitating Huntington's disease. This affliction envelops its victim by riddling them with involuntary movements, impaired speech and dementia. This is the case of a 22 year old male - 'Nathan' - who grew up watching his mother 'Eva', deteriorate into a helpless individual after the onset of Huntington's disease. Nathan did not seek a genetic test to establish whether he had the specific gene causing Huntington's disease, however, he was aware that because his mother had the condition, there was a possibility that he could have inherited the gene - although there was no certainty. Nathan applied for a job in the public sector: "After matriculating from college with above-average marks, Nathan applied for acceptance into his long-chosen career in the public sector and was placed in the top 5% of applicants. The final entry requirement was to pass the medical examination.

In response to the requirements of the medical examination, Nathan submitted that there was a history of Huntington's disease in the family. The fact that Nathan was bright and a high-achiever did not appear to be enough. The department concerned informed Nathan that the job was his on the condition that he submitted to a genetic test and that it subsequently proved negative for the genotype that causes Huntington's disease.

Nathan did not undergo the test, but began an appeal process through the Department - eventually being employed after a lengthy process, but on the proviso of a number of conditions being met. He gladly accepted. The case of Nathan shows that genetic discrimination does not merely require actual genetic conditions to be present, but perceived conditions can be the basis of discriminatory treatment as well.

Additional Information:
Huntington's disease is a progressive brain disorder. This disease is inherited in an autosomal dominant pattern which means one copy of the altered gene in each cell is sufficient to cause the disorder. An infected person usually inherits the gene from one affected parent. Huntington's disease usually is an adult-onset disorder, which means it presents in a person's thirties or forties. This is a progressively degenerative disease where affected individuals may have trouble walking, speaking, and swallowing. People with this disorder typically also experience changes in personality, and a decline in thinking and reasoning abilities. As the disease progresses involuntary jerking movements become more pronounced. Deterioration of the previously mentioned faculties continue until death.

An optional idea would be to have the teacher portray this information as a doctor informing the “public” in order to model role-playing.

ACTIVITY:
In this activity you will either be representing Nathan as a concerned patient with a genetic disorder or an interest group attached to the controversial issue of genetic testing versus the privacy rights of the individual. You have been assigned to one of the interest groups below. For the purpose of this case study, your group is in attendance at a Presidential advisory committee meeting (in the near future), aimed at reviewing the federal legislation regarding the discrimination of individuals based on genetic information: HR493, and evaluating its strengths and weaknesses. You should consider yourself an advocate and representative for the group to which you have been assigned. It is your job to review your group’s assigned materials and present that group’s view to the advisory committee to its strongest and most persuasive form. “Does your group agree with the legislation as is, or would your group push for changes to this legislation? What possible changes, if any, should there be?”

This is a role playing exercise: You should strive, as much as possible, to adopt the perspective of a member of your interest group for the duration of this exercise whether or not you really do agree with the position your group would advocate.

INTEREST GROUPS:
Nathan
Insurance Co.
Employer
Council for Responsible Genetics
ACTIVITY SCHEDULE:
1. (20 – 30 minutes) As an individual, read through the introductory paragraph, the assigned reading for your group, and the text on the legislation known as HR 493. *(You do not need to read the material from all of the different interest groups, only the group to which you have been assigned!)*

   Write down the main claims that represent the view your interest group would take on genetic testing vs individual privacy rights. Once you are done with your claims think about the claims that your opponent could make to argue against you.

2. (20 minutes) Get together with the other members of your group to discuss how you might best make the case for your group’s perspective on this issue. As a group, you should work to put together a brief presentation (2-3 minutes) that will explain and justify your interest group’s position. You should consider this to be a persuasive presentation to the Presidential Advisory Review committee to either keep HR493 as is, or propose changes to this legislation.

3. (20 minutes) After preparing their presentations, each group will present its case to the other students in class. Members of the “audience” will have a brief opportunity to pose questions or to raise objections after each presentation.

4. (Remainder of class) Case study “debriefing”. Students will have an opportunity to discuss the issue, the different interests and values involved outside of their adopted roles. Students will begin their reflection before the end of class. This reflection is due at the start of their next class period.

Student reflection should include a discussion of:
   a) Their interest group topic and role in the activity
   b) Description of their personal feelings on this controversial issue, and how their opinions may or may not have changed during the course of this activity
   c) What their favorite part of the activity was
   d) Provide comments (if any) to help amend this activity for the future
NATHAN’S PERSPECTIVE:
[Dramatization - representing a patient’s perspective of privacy rights. Based on true story]

My name is Nathan. I am 22 years old. I would like to tell my story of how Huntington’s disease has impacted my life in order to aid this advisory committee in considering the perspective of a patient’s right to privacy.

I spent my high school years taking care of my mother who had Huntington’s disease. I watched her wither away into a woman I did not recognize. Before she died I witnessed her dealing with bouts of dementia, involuntary muscle contractions, and a complete inability to care for herself and her family.

After my mother passed away I attended college and decided not to seek genetic testing to determine if I too, had the gene for Huntington’s. I realize there is a possibility that I have the disease, but it is a one in two chance that I will be free of Huntington’s. I have seen first hand what this disease does to an individual and choose to live my life as normal as possible.

After college I chose to seek employment with Wolf Industries. While in college I achieved a grade point average of 3.98 and was placed in the top 5% of applicants for this position. The final entry requirement that I was asked to complete was a full medical history exam. I revealed then that there was a history of Huntington’s disease in my family. I was informed that the position was mine if my medical history exam came back negative. I chose at the time not to undergo testing because I felt that it was not the industry’s right to require this information. I do not wish, nor think, its fair for anyone to be discriminated based on their genetic makeup. I felt that I would be a good employee based on my skills and achievements and wished that my medical history not be involved in their decision to hire me.
INSURANCE COMPANY PERSPECTIVE:

Health insurance helps protect the insured from high medical care costs. Many people in the United States get a health insurance policy through their employers. In most cases, the employer helps pay for that insurance. Insurance through employers is often with a managed care plan. These plans contract with health care providers and medical facilities to provide care for members at reduced costs.

You can also purchase health insurance on your own. It usually costs you more than employer-based insurance. People who meet certain requirements can qualify for government health insurance, such as Medicare and Medicaid. If you do not have health insurance, you must pay your medical bills directly or rely on health care providers or organizations that donate care.

Insurers face strong economic incentives to identify individuals perceived to be at increased risk for ill health in the future. After an applicant completes an insurance application, the insurance company begins to evaluate the case. This evaluation is called "underwriting." An "underwriter" reviews the application and any other questions or exams that were done. Once all required information has been received (lifestyle questionnaires, pre-policy health check-ups), the insurance company makes a decision regarding whether, and at what rate, the applicant qualifies for the insurance. The data collected allow the insurer to assess whether the applicant is a higher than average risk to them.

Underwriting attempts to classify risks based upon the likelihood of death in order to charge people accordingly to the potential risk. This not only protects the life insurer, but also those that are least likely to die because they pay less. It only makes sense that a person with a past history of a serious illness is going to be charged a much higher premium than the healthy person. If you were the healthy person with the least likelihood to die would you want to pay the same amount as the person who had a serious illness? No. In addition group life insurance doesn't individually underwrite each person, if you're healthy, you will end up paying for those that aren't so healthy, often times doubling your rate.

Genetic testing would indicate to insurers those potential policyholders that would be making more claims to their insurance companies in the future to pay for medical bills due to their genetic conditions. In addition, if society decides that everyone is entitled to comprehensive health care in the future, then private health insurance companies would be put out of business and all members of society must be prepared to bear the financial burden.
EMPLOYER PERSPECTIVE:

From an employer’s perspective, there are clear economic incentives associated with the use of genetic information about employees and potential employees. Such information offers employers an opportunity to exclude from the workforce individuals who have been identified as being at risk of developing a genetic condition that may affect their future capacity for work. Thus, there is potential for an organization to reduce or avoid the costs associated with absenteeism, sick leave entitlements, and staff turnover.

An employer’s desire to obtain genetic information may also be motivated by occupational health and safety factors. For example, an employer may wish to use genetic information to determine whether or not an employee has a genetic predisposition that may pose a safety risk to the employee, co-workers or the public or that may render the employee particularly susceptible to workplace hazards.

At a more general level, it may be argued that an employer has a legitimate interest in obtaining as much information as possible about a prospective employee in order to maximize its prospects of selecting the best possible person for the job. The use of pre-employment medical, psychological and even drug tests is already widespread in many industries. Genetic testing may simply be seen as the next logical step along this continuum.
COUNCIL FOR RESPONSIBLE GENETICS (CRG):

Privacy rights advocacy organization. CRG has been aimed at advancing the public interest in biotechnology since 1983 and fostering public debate about the social, ethical, and environmental implications of genetic technologies.

GENETIC TESTING, DISCRIMINATION, AND PRIVACY

The concept of “genetic discrimination” only recently entered our vocabulary. But the problem is well documented. In as many as five hundred cases, individuals and family members have been barred from employment or lost their health and life insurance based on an apparent or perceived genetic abnormality. Many of those who have suffered discrimination are clinically healthy and exhibit none of the symptoms of a genetic disorder. Often, genetic tests deliver uncertain probabilities rather than clear-cut predictions of disease. Even in the most definitive genetic conditions, which are few in number, there remains a wide variability in the timing of onset and severity of clinical symptoms. Employers have access to medical/genetic information, which may be used to discriminate against their employees.

The current patchwork of federal laws, including the Americans with Disabilities Act and the Health Insurance Portability and Accountability Act, hardly scratch the surface of the problem. While President Bush has just signed the Genetic Information Nondiscrimination Act of 2008 which addresses the use of genetic information by insurance companies, the most effective way to prevent the misuse of genetic information is to keep it confidential and securely out of the reach of outsiders. The right of privacy is recognized in common law and the Fourth and Fifth Amendments of the Constitution.

Such treatment in employment is abhorrent and raises a few points of particular concern. This treatment creates a new potential underclass. An individual that has no present manifestations of an illness that they may or may not eventually get is being treated differently to others in the same position. Such an approach denies the ability of potentially excellent employees to fill a job vacancy, based on one genetic factor (or as in Nathan's case, a 'perceived' genetic factor). So in Nathan's case, his ability to contribute to the organization is not seen as being more significant than the possibility that he may have an 'abnormal' genetic composition - a perplexing proposition.

This form of genetic discrimination in employment is problematic for further reasons. Nathan was firstly denied employment and then, was provided with conditional employment because he may have the gene that causes Huntingdon's disease. This is problematic because other employees are not treated in the same manner. Such an approach to Nathan's application and subsequent employment is concerning because, it is not the case that this differential treatment exists because there is a problem inherent in the person themselves, or their ability to fulfill required tasks. Every individual is susceptible to certain ailments and has certain predispositions, but the technology does not yet exist to screen other applicants for their own possible future risks. Therefore, it is a tenuous position to attach conditions to some individuals and not others in employment merely because the technology and knowledge exists to detect some genetic diseases, but others cannot have their own risks similarly assessed. In this context, it is significant that researchers estimate that each human being carries at least 20 'defective' genes that may indicate predisposition to disease, however, such genes have yet to be 'mapped'- thus every individual could theoretically be susceptible to exclusion in employment on the basis of genetic discrimination if such issues remain unregulated.
In order to begin to understand this issue it is imperative that you become familiar with the current legislation concerning the discrimination of individuals based on genetic information. The following is the legislation known as G.I.N.A., passed by both congressional houses and approved by President Bush in 2008

H.R. 493: Genetic Information Nondiscrimination Act of 2008 (GINA)
To prohibit discrimination on the basis of genetic information with respect to health insurance and employment.

Title I - Genetic Nondiscrimination in Health Insurance
Section 101 -
Prohibits a group health plan from requesting or requiring an individual or family member of an individual from undergoing a genetic test. Provides that such prohibition does not: (1) limit the authority of a health care professional to request an individual to undergo a genetic test; or (2) preclude a group health plan from obtaining or using the results of a genetic test in making a determination regarding payment. Requires the plan to request only the minimum amount of information necessary to accomplish the intended purpose.

Allows a group health plan to request, but not require, a participant or beneficiary to undergo a genetic test for research purposes if certain requirements are met, including: (1) the plan clearly indicates that compliance is voluntary and that noncompliance will have no effect on enrollment status or premium or contribution amounts; (2) no genetic information collected or acquired is used for underwriting purposes; and (3) the plan notifies the Secretary of Health and Human Services that it is conducting activities pursuant to this exception and includes a description of the activities.

Prohibits a group health plan from requesting, requiring, or purchasing genetic information: (1) for underwriting purposes; or (2) with respect to any individual prior to such individual's enrollment in connection with such enrollment (provides that incidentally obtains such information is not a violation).

Applies such prohibitions to all group health plans, including small group health plans.
Provides that any reference to genetic information concerning an individual or family member includes genetic information of: (1) a fetus carried by a pregnant woman; and (2) an embryo legally held by an individual or family member utilizing an assisted reproductive technology.
Authorizes a penalty against any sponsor of a group health plan for any failure to meet requirements of this Act. Allows a waiver or limitation on such penalty if the failure was not discovered after exercising reasonable diligence or was due to reasonable cause.

Section 102 -
Prohibits: (1) a health insurance issuer offering health insurance coverage in the individual market from establishing eligibility rules for enrollment based on genetic information; (2) discrimination on the basis of genetic information for health insurance offered in the individual market in the same manner as such discrimination is prohibited for group coverage; and (3) the imposition by a health insurance issuer offering health insurance coverage in the individual market of a preexisting condition exclusion on the basis of genetic information.
Applies such requirements to nonfederal governmental plans.

Section 104 –
Prohibits an issuer of a Medicare supplemental policy, on the basis of genetic information, from: (1) denying or conditioning the issuance or effectiveness of the policy, including the imposition of any exclusion of benefits based on a preexisting condition; or (2) discriminating in the pricing of the policy, including the adjustment of premium rates; (3) requesting or requiring an individual or a family member to undergo a genetic test; or (4) requesting, requiring, or purchasing genetic information for underwriting purposes or for any individual prior to enrollment.

Section 105 -
Requires the Secretary of Health and Human Services to revise Health Insurance Portability and Accountability Act of 1996 (HIPAA) privacy regulations to: (1) treat genetic information as health information; and (2) prohibit the use or disclosure by a group health plan, health insurance coverage, or Medicare supplemental policy of genetic information about an individual for underwriting purposes.

Section 106 -
Requires the Secretaries of Health and Human Services, Labor, and the Treasury to ensure that their regulations, rulings, and interpretations under this title are administered so as to have the same effect at all times and that they adopt a coordinated enforcement strategy.

(cont’d on next page)
Title II - Prohibiting Employment Discrimination on the Basis of Genetic Information

Section 202 -
Prohibits, as an unlawful employment practice, an employer, employment agency, labor organization, or joint labor-management committee from discriminating against an employee, individual, or member because of genetic information, including: (1) for an employer, by failing to hire or discharging an employee or otherwise discriminating against an employee with respect to the compensation, terms, conditions, or privileges of employment; (2) for an employment agency, by failing or refusing to refer an individual for employment; (3) for a labor organization, by excluding or expelling a member from the organization; (4) for an employment agency, labor organization, or joint labor-management committee, by causing or attempting to cause an employer to discriminate against a member in violation of this Act; or (5) for an employer, labor organization, or joint labor-management committee, by discriminating against an individual in admission to, or employment in, any program established to provide apprenticeships or other training or retraining.

Prohibits, as an unlawful employment practice, an employer, employment agency, labor organization, or joint labor-management committee from limiting, segregating, or classifying employees, individuals, or members because of genetic information in any way that would deprive or tend to deprive such individuals of employment opportunities or otherwise adversely affect their status as employees.

Prohibits, as an unlawful employment practice, an employer, employment agency, labor organization, or joint labor-management committee from requesting, requiring, or purchasing an employee's genetic information, except for certain purposes, which include where: (1) such information is requested or required to comply with certification requirements of family and medical leave laws; (2) the information involved is to be used for genetic monitoring of the biological effects of toxic substances in the workplace; and (3) the employer conducts DNA analysis for law enforcement purposes as a forensic laboratory or for purposes of human remains identification.

Section 206 -
Requires an employer, employment agency, labor organization, or joint labor-management committee that possesses any genetic information about an employee or member to maintain such information in separate files and treat such information as a confidential medical record and from disclosing such genetic information, except: (1) to the employee or member upon request; (2) to an occupational or other health researcher; (3) in response to a court order; (4) to a government official investigating compliance with this Act if the information is relevant to the investigation; (5) in connection with the employee's compliance with the certification provisions of the Family and Medical Leave Act of 1993 or such requirements under state family and medical leave laws; or (6) to a public health agency.

Section 207 -
Sets forth provisions regarding enforcement of this Act.

Section 208 -
Establishes the Genetic Nondiscrimination Study Commission six years after enactment of this Act to review the developing science of genetics and to make recommendations to Congress regarding whether to provide a disparate impact cause of action under this Act. Authorizes appropriations to the Equal Employment Opportunity Commission (EEOC) to carry out this section.
POSSIBLE EXTENSION ACTIVITIES:
1. Extend discussion of the ethics or other uses of genetic testing with the viewing of GATTACA
2. Extend discussion of genetic testing by doing internet site exploration to look at cost, services and any other additional information that students are interested in.
   DNA Testing Centre, Inc
   http://www.dnatestingcentre.com
   Know Your Genetic Risks
   http://www.newhopomedical.org
   Genetic Testing - 23andMe
   Understand Your Genetic Makeup. The First Personal Genome Service.
   http://www.23andMe.com
   Genetic Testing
   Advances in genetic testing have improved doctors’ ability to diagnose and treat certain illnesses.
   www.kidshealth.org/parent/system/medical/genetics.html
   Genetic Testing – Genetics Home Reference
   What is the cost of genetic testing, and how long does it take to get the results? Will health insurance cover the costs of genetic testing? 
   http://www.ghr.nlm.nih.gov/handbook/testing
3. Extend discussion of comprehensive healthcare, the impact it would have on this country, and presidential candidate proposals

Works Cited:

Informational Websites:
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www.murdoch.edu.au/elaw/issues/v7n2/stulic

Cleveland Clinic Journal of Medicine
http://www.ccjm.org/pdffiles/Fisher104.pdf

CRG-Council for Responsible Genetics
www.gene-watch.org/programs/privacy.html


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Images:
http://images.google.com/imgres?imgurl=http://ndn.newsweek.com/media/76/genetic-testing-health_HE01-vl-vertical.jpg&imgrefurl=http://www.newsweek.com/id/131743&h=420&w=300&sz=10&hl=en&start=24&um=1&tbnid=nITgdsNUEGNMZM:&tbnh=125&tbnw=89&prev=/images%3Fq%3Dgenetic%2Btesting%26start%3D20%26ndsp%3D20%26um%3D1%26hl%3Den%26sa%3DN