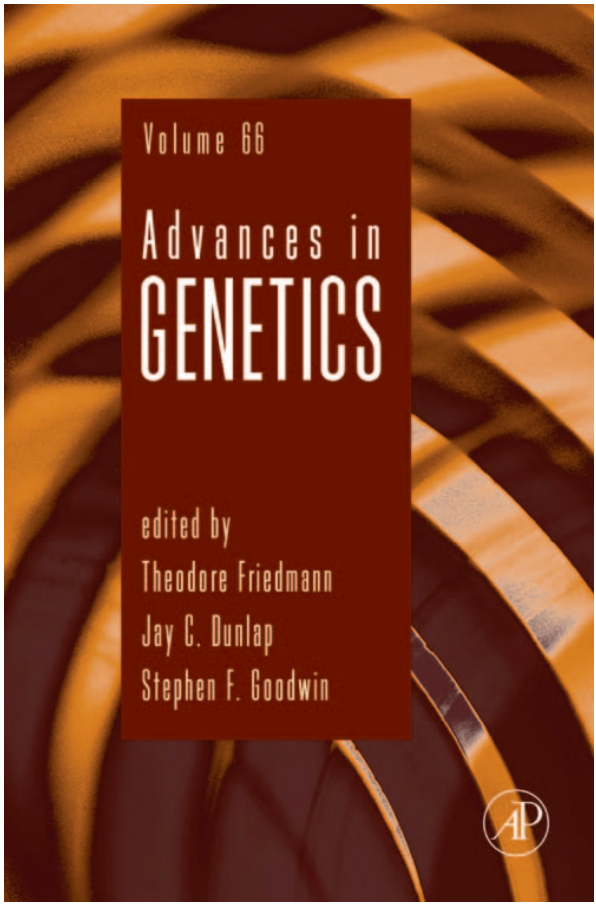

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2 Resources and Strategies to Integrate the Study of Ethical, Legal, and Social Implications of Genetics into the Undergraduate Curriculum

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ABSTRACT

Gene therapy, genetically modified organisms, and the privacy of an individual's genetic information are just a few of the developments emerging from recent advances in molecular genetics that are controversial. Oversight and regulation

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of emerging technologies are the responsibility of both experts and the general public who both need to understand the science and the societal impact of its use. The study of ethical, legal, and social implications (ELSI) of advances in genetics provides a very powerful pedagogical tool to accomplish two goals. These are, first of all, to interest nonscientists in genetics and engage them in learning the science behind the ELSI developments they are considering, and secondly, to broaden the perspective of science students to consider the history and social consequences of the science they are studying. The resources and strategies presented in this chapter for teaching ELSI issues that arise in modern genetics are designed to aid in accomplishing these goals throughout the undergraduate curriculum. This chapter provides (1) a set of nine ELSI topic modules that can be incorporated into courses for both majors (from introductory to graduate level) and nonmajors and (2) examples of course pedagogy for specific classes.

I. INTRODUCTION

There is wide agreement, that in order to fully participate in a democratic society, a citizen must be knowledgeable and well informed (Dolan, 2008; Rutherford, 1990). An understanding of basic science is important as our society is ever more dependent on technological advances. In particular, recent advances in our understanding of the molecular mechanisms of inheritance are leading to practical applications in society, which will impact us all. Recent surveys suggest that, while the interest level is high, the general level of understanding of genetic concepts is woefully low in the general populace (Bowling *et al.*, 2007, 2008; Dienstag, 2008). In general, a typical nonexpert not surprisingly acts on a need-to-know basis, becoming well educated on the mechanisms of a particular disease if they or someone close to them is affected but not becoming broadly educated in anticipation of important developments that do not directly impact their life. Recent focus on ethical, legal, and social implications (ELSI) topics emerging from the Human Genome Project (HGP) has resulted in a powerful interdisciplinary mechanism for addressing this problem.

Note: the "problem" is more complex than generally recognized by scientists. It is not just that the public lacks an understanding of the "facts" of genetic mechanisms but also that scientists are poorly prepared to consider the applications or the implications of their work in society. Thus ELSI issues provide a very powerful pedagogical tool to accomplish two related goals. One is to interest nonscientists in genetics and engage them in learning the science behind the ELSI developments they are considering, and the second is to broaden the perspective of science students to consider the history and social consequences of the science they are studying. As educators we bear

responsibility for ensuring our students graduate with our best understanding of the concepts, theories, and content of our disciplines. Can we honestly claim to have done that if the students are insensitive to other perspectives on this knowledge?

There has been substantial progress in the development of ELSI pedagogies, which either focus primarily on ELSI issues (the Genetics and Society type of course) or integrate these issues into "regular" genetics courses. Much of this progress is the result of the earmarking of 3–5% of the HGP budget for funding ELSI projects. One such project was the 1996–2006 Dartmouth Ethics Institute ELSI Program of workshops in which over 240 university and college faculty attended a 3–5 day workshop in preparation for implementing ELSI issues in courses at their own institution (Donovan and Green, 2008). The interest in ELSI issues as part of the undergraduate curriculum is increasing and there are many articles that provide useful resources for teaching particular topics (Haga, 2006) or offer plans to incorporate ELSI issues into a particular course (Galbraith, 2008). Our goals in this chapter are twofold: (1) to provide a set of nine ELSI topic modules that can be incorporated into courses for both majors (from introductory to graduate level) and nonmajors, and (2) to provide specific examples of course pedagogy and organization.

In Section II, two independent modules (see Sections II.A and II.B) are followed by five modules covering issues related to genetic testing and privacy (see Sections II.C–II.G). Two additional modules provide examples of more general pedagogical approaches (see Sections II.H and II.I).

Section III outlines two specific approaches to integration of ELSI issues into (A) General education courses for nonmajors and (B) Genetics courses for Bioscience majors.

II. RESOURCES

A. Eugenics

Teaching the history of a discipline can be a very effective mechanism of building an understanding of the current "state of the field." It has been standard practice in teaching genetics courses to start with Mendelian genetics and move through classical genetic analysis, to the molecular basis of inheritance (genetics and now genomics). Most genetics texts still follow this approach although the number of pages devoted to pre-1953 has been plummeting.

Over recent years another, less laudatory, chapter in the history of genetics has been drawing scholarly and public attention. Eugenics, the science of improving the human gene stock through selective breeding, was vigorously practiced during the late nineteenth and early twentieth centuries notably in the

United States and United Kingdom (Carlson, 2001). The misguided application of Mendelian genetic principles in an attempt to remove "undesirable" people from society and thus enhance society provides a powerful mechanism to alert students to the potential pitfalls in applying simple scientific principles to a poorly understood social situation (Garver and Garver, 1991). A study of the eugenics movement also illustrates how powerful and dangerous the combination of political and academic leaders with (erroneous) scientific evidence can be. A module on eugenics can be readily integrated into a standard genetics course and can be particularly useful as it fits early in the course before the background information necessary for a comprehensive understanding of molecular techniques is reached.[1] It is also a fairly easy module for an instructor uncomfortable venturing out of their disciplinary training to develop.

There are substantial resources available online. For example, the Dolan DNA Learning Center (DNALC), an operating unit of Cold Spring Harbor Laboratory, maintains an online catalog of educational resources. These include the DNALC Eugenics Archive http://www.dnai.org/e/index.html, which contains many original documents for study. A homework research assignment in which the students independently locate answers, using the documents on the CSH Web site, to questions such as "Which groups were considered to have the highest/lowest intelligence", "What was the scientific evidence used to justify this conclusion?" can form the basis for a lively discussion. During the next class students work in small groups to generate group answers to the questions and discover that some of them have slightly different answers, as there may be more than one source for a response and it depends which one they found. However, the prejudices of the time immediately become apparent and students are often startled at how brazen they seem to us.

Students tend to be very familiar with the eugenics of Nazi Germany and the Holocaust, but less so with the consequences of American eugenics, laws that affected the education, reproduction and freedom of individuals deemed to be "unfit" at that time. A short, and powerful, web exercise is to assign students to find the eugenics laws that were passed in a particular state (ideally their home state but some management is required to spread out the research), what the powers of the laws were, when they were repealed and if any official apology has been offered.

Another pedagogical approach is to focus on how different countries constructed a solution to the "problem of the unfit." The American and European approach was to try to decrease the number of inferior individuals by

[1] I (J. M. G.) teach eugenics during the first week of classes of the spring semester, which, in our schedule, includes Martin Luther King Day. This allows me to acknowledge the use of science in the racism of the past, and to pay respect to the work of the Civil Rights Movement in overcoming that legacy, in a science course.

isolating them, preventing them reproducing and thus preventing more being born (Carlson, 2001; D'Antonio, 2005; DNA: Pandora's Box, 2003). Ultimately the Final Solution was genocide. This approach is predicated on an us/them dichotomy in which the genetic determinism of their unfitness is never questioned and an important goal is to not allow the unfit to pollute the gene pool of the virtuous group in society.[2] A somewhat different approach, taken by the Colonial British in Australia to the "problem" of the native Aborigines, is presented in the movie "A Rabbit-Proof Fence" (Miramax, 2003). Children of mixed parentage were forcibly removed from their families, made wards of the British Governor and educated in special schools in preparation for greater integration in society. One scene, where the Governor is lecturing a group of wealthy white women sponsors on the inheritance of race, is a particularly compelling tool for use in discussion of various beliefs in the genetic basis of race. Finally, discussion of the eugenics movements of the past can set the stage for subsequent ELSI topics in a course. For example, see Section II.G.

B. Human ancestry and evolution

Students are often fascinated by a review of the history of human migration around the world and they are particularly intrigued by the use of molecular markers to trace the ancestry of human populations. The National Geographic Web site provides online access to information about the work of Spencer Wells and his colleagues to sample DNA from isolated human populations around the world. Students read *The Journey of Man, a Genetic Odyssey* (Wells, 2003) in preparation for viewing a 2-h PBS companion film at the next class meeting. Alternatively, students may view a reserve copy of the film outside of class at a campus media center. Both the book and the film are aimed at a general audience. Introductory material about DNA structure and function is appropriate for first year college students without previous genetics coursework. The use of DNA markers is explained; DNA sequence analysis is demonstrated. The book and companion film together provide an excellent opportunity to assess student familiarity with basic genetic concepts and modern DNA methods (see also Human Origins, http://www.dnai.org/d/index.html).

The National Geographic Web site also provides information about the progress of the current Genographic Project to analyze field-collected data from indigenous and traditional peoples around the world as well as data collected from the general public. The project is anonymous, nonmedical, nonpolitical, nonprofit, and noncommercial; results of the project will be published following

[2]In a genetics course, one can include an interesting aside to the concept of hybrid vigor in plant breeding and how Mendelian genetics could be used to argue for such different conclusions in plants and humans in the U.S.

scientific peer review and placed in the public domain (https://www3.nationalgeographic.com/genographic; Wells, 2006). However, the collection of DNA data from Native American tribes has been problematic. Genographic origin stories told by DNA can clash with long-held beliefs vital to preserving Native American culture and may jeopardize land rights and other benefits (Harmon, 2006).

Alexander Werth has recently reviewed the implications of the Genographic Project for the study of human evolution (Werth, 2008). Questions about human evolution typically arise when students are confronted with DNA evidence from comparative genomics studies. Students are baffled by reports that 90% of genes are shared between mouse and man (Waterston *et al.*, 2002), and 99% of genes are shared between chimpanzee and man (Lander *et al.*, 2005). Evolutionary developmental biology (Evo Devo) provides insight into the relationship between genes and evolution and is a useful point of entry to the study of evolution for students with a broad range of scientific backgrounds (Carroll, 2008; Hunter *et al.*, 2008a). Students find the work of Sean Carroll to be accessible and engaging, regardless of their prior level of preparation in biology. In particular, Carroll's book, *The Making of the Fittest* (Carroll, 2006) can be useful for first and second year students enrolled in a general education course designed to fulfill a natural science in perspective requirement. Students are fascinated to learn that a small number of primitive genes led to the development of organs and appendages in all animal forms (Carroll, 2005).

Sean Carroll has two projects expected to be available in 2009. WGBH NOVA is developing a 2-h special program based on Sean Carroll's two books, *Endless Forms Most Beautiful* (2005) and *The Making of the Fittest* (2006). Carroll's new book, *Remarkable Creatures: Epic Adventures in the Search for the Origins of Species*, will also be published in early 2009. These should also be excellent sources for use in this module.

The potential to sample an individual's genome in order to identify that individual and determine aspects of their predisposition to health or inherited diseases gives rise to a series of five modules in issues relating to *genetic testing and privacy*.

C. Genetic identification: Forensics

Discussions of what is, or soon will be, possible with regard to genetic testing and individual identification can take many different approaches. Students are very familiar with the concept of individual identification through fingerprints and retinal scans. They have grown up with the various CSI series and the ubiquitous swabbing and DNA analysis that invariably contributes to a successful

conclusion of each episode. Given that the technology for individual identification is well established, it is the utilization and regulation of that technology that is currently under consideration. Routine uses of genetic analysis for identification purposes include: prosecution of suspects in criminal investigations; proof of innocence in cases of wrongful conviction of people in the past (Dwyer *et al.*, 2000; The Innocence Project—http://www.innocenceproject.org/); identification of crime or disaster victims; identification of military personnel; and proof of familial relationships (paternity and immigration cases). This type of use of genetic information is uncontroversial and has great utility; however, other applications of genetic testing and databases established for forensic purposes cause more concern even among young adults.

American society is based on a very strong concept of individual rights, carefully overseen by the American Civil Liberties Union. Privacy is established in the Constitution in various ways including the fourth Amendment offering protection against unlawful search and seizure. This sensitivity has prevented widespread universal testing of the general population around a crime scene, an approach that has been utilized to successfully apprehend criminals in many countries in Europe (McCabe and McCabe, 2008; see Chapter 11 in Mehlman *et al.*, 2006). A role-playing exercise where all male students are required to submit samples in a fictional rape investigation quickly reveals serious tensions about submitting to such testing. Is it unfair that only men are at risk of their genetic information becoming public? Should there be genetic databases made from newborn blood samples so that everyone is already "on file"? Is it permissible for law enforcement officers to collect "abandoned" DNA samples on coffee cups and analyze them? (Once "abandoned," the coffee cup and the cells it carries are not subject to individual protection through ownership).

One useful technique to make this discussion relevant to students is to propose a college identification system (see strategies section later). Using microsatellite markers, like those used in CODIS that do not have any medically predictive value, as part of a College identification system seems like a good idea as it would allow campus security to identify the person(s) who threw a rock through the professor's office window. But what if all those beer cans on the quad after a party weekend were analyzed to catch underage revelers?

Students tend to be more comfortable than their elders with decreased privacy as members of their generation actively participate in information sharing Web sites like Facebook and YouTube. This tendency, toward information exchange as a form of social networking, is currently being exploited by genetic testing companies. The firm 23andMe, which advertises that their genetic test results give information about 80+ diseases, traits and conditions, has been running "spit parties" to promote their product suggesting that people will form social groups on the basis of the alleles they share, as in "You are invited to join the group of Slow Caffeine Metabolizers" (Salkin, 2008). A discussion

based on the students' readiness to get involved with such technologies and their concerns about the privacy of such information once collected links well to the next module on genetic testing for disease related markers.

D. Genetic testing: Simple inherited diseases

This module is designed to familiarize students with online medical genetics resources and the privacy issues that arise from their use. In addition, students get the opportunity to explore relevant terms encountered in the popular media such as "personalized medicine" (Kaiser, 2008; Lee and Morton, 2008) or "genomic medicine" (Hunter *et al.*, 2008b; McBride *et al.*, 2008).

Your Genes, Your Health (YGYH) is an online resource targeted to patients and families who are looking for easy-to-understand information about a specific genetic disorder (http://www.ygyh.org). Information for each disorder is organized according to questions visitors may have about the disorder: What is it? What causes it? How is it inherited? How is it diagnosed? How is it treated? What is it like to have it? Where can I get more information? YGYH focuses on 15 disorders, which were chosen using three criteria: high incidence rate, known genetic cause, and severity of the phenotype (symptoms). The 15 disorders include Alzheimer disease, beta-thalassemia, cystic fibrosis, Down syndrome, Duchenne/Becker muscular dystrophy, Fragile X syndrome, hemochromatosis, hemophilia, Huntington disease, Marfan syndrome, neurofibromatosis, phenylketoneuria (PKU), polycystic kidney disease, sickle cell disease, and Tay–Sachs disease. In each case, the participation of genetic foundations or organizations was enlisted for information and access to patients and/or physicians for video interviews. The Web page for each disorder comprises a number of resource pages that provide in-depth information. The first "page" provides quick facts for casual browsing. Subsequent pages include detailed animations to help visitors visualize the unseen world of genes and molecules and explain the biology of the disorder. Video interviews with researchers and patients provide insiders' views on genetic disorders. Links help users find support groups and additional information.

Assignment of specific genetic diseases to each of a number of small groups of students permits students to present material to the class and share what they have learned. Alternatively, individual writing assignments can be designed to include a wider range of human genetic diseases (Burke *et al.*, 2006; Pagan, 2006).

This module can be expanded to include the study of DNA data collection projects described as Biobanks (Rothstein, 2006). These projects include the Iceland Biobank (deCODE), the UK Biobank, and The Human Genome Diversity Project. Each of those projects can be assigned to a small group of

students for presentation to the class. Students may role-play as investigative reporters and opt for a news program format presentation. Alternatively, students may assume roles as scientists and participants in each of the projects, in order to demonstrate ELSI issues associated with Biobanks (Haga and Beskow, 2008).

Students are increasingly aware of press about commercial DNA services available to the public, such as 23andMe, deCODEme, and Navigenics (Pollack, 2008; Wade, 2007; Wolfberg, 2006). The Icelandic company deCODE Genetics offers a service called deCODEme, which will assess a person's genome for risk of common diseases, bodily traits like hair and eye color, and ancestral origins. A similar service is offered by 23andMe, and a third company, Navigenics, focuses on disease genes. Discussion of the regulatory action taken by California and New York against these companies (to prevent solicitation of customers in those states until an appropriate license to offer medical tests was obtained) will inform students about issues associated with the collection of personal genetic data (Wadman, 2008). Privacy issues should be explored in the context of the data collection processes associated with each of these projects (Greely, 2007; Kaiser, 2004; Lin *et al.*, 2004; Roche and Annas, 2006).

E. Genetic testing and counseling

Until recently most genetic testing was a carefully controlled procedure conducted by medical professionals. Testing was only undertaken on individuals either affected or at risk, for an inherited disorder for which a genetic test was available. As discussed above, a new market in commercial genetic testing has developed where relatively unregulated screening of DNA isolated from saliva or cheek cell swabs, submitted directly to a company by the customer, is undertaken with no oversight by a physician or any regulatory agency. As genetic information can be powerful, affecting people beyond the individual tested, and interpreted in very different ways it is very important to consider how this information is distributed.

Discussions on the technologies and power of genetic testing (module 4) generally result in strong agreement as to the necessity of genetic privacy: that one's genome should be carefully protected under personal control as given under the American Society of Human Geneticists (ASHG) statement—"Genetic information, like all medical information, should be protected by the legal and ethical principle of confidentiality" (American Society of Human Geneticists, http://www.ashg.org/).

To introduce students to the many complications of genetic testing it is useful to get them to consider case studies that raise the ambiguities faced by genetic counselors and physicians every day. The general methodology of genetic testing can be introduced using a specific example, e.g., the breast cancer

susceptibility genes *BRCA1* and *BRCA2*. Patients desiring a genetic test are interviewed by a counselor and a family history obtained. Genetic testing is most powerful when the allele associated with increased cancer risk in a particular family is known. Thus it is preferable that affected members of the family be tested first and, if a mutant *BRCA1* or *BRCA2* allele is detected, then the proband (the person requesting testing) can be tested for that allele. Results are shared with the individual at a follow-up counseling appointment.

Some scenarios for consideration:

a. A woman who has had breast cancer comes in for testing but, posttesting, decides she cannot cope with the information and does not come back for her results, which are negative. Knowing how relieved she would be with the negative result, should the counselor contact her? Months later, the woman's daughter comes in requesting testing and she intends to undergo a double mastectomy if she is found to be at increased risk. Her mother still does not know, or want to know her status, but testing the daughter will "inform" to the mother. Plus, mother's test was negative so her daughter will not gain much information from testing although that information is confidential. To whom does the counselor owe the most responsibility?
b. A woman, whose relatives have been affected with breast and ovarian cancer linked to a known mutant *BRCA2* allele, is tested. She comes in for the (negative) results and is accompanied by her sister who now also wishes to be tested but you judge to be too emotionally unstable to cope with a positive result. As the counselor do you have "right" to make that determination?
c. A woman, who is 8 weeks pregnant, is diagnosed with breast cancer and wants genetic testing. She says that if she tests positive for a mutant *BRCA1* or *BRCA2* allele she will request testing for the fetus. Your response?

A physician's or genetic counselor's responsibility to their patient for confidentiality and thus genetic privacy is sometimes in contradiction to what most people would be perceive as a greater good. For example, when a patient is diagnosed with a disease that has a well-understood pattern of inheritance (e.g., certain cancer genes) this has obvious implications for other family members, particularly any offspring of the affected individual (aggressive early screening might give significant increase in lifespan). Normally, one could expect a person to have the best interests of relatives at heart and that they would inform their relatives as appropriate so that they could all benefit from the information. However, not all families function optimally and in cases where the affected individual would not inform others of a serious risk doctor (counselor)/patient privacy may result in serious harm to another identifiable individual. Thus, through a series of test common law cases, the ASHG policy has been developed to include conditions where disclosure of private genetic information is allowed.

Disclosure is permissible. . .

- Where attempts to encourage disclosure on the part of the patient have failed
- Where serious and foreseeable harm is highly likely to occur
- Where the at-risk relative is identifiable
- Where either the disease is preventable/treatable or where early monitoring will reduce the genetic risk
- Where the harm that may result from failure to disclose outweighs the harm that may result from disclosure

After consideration of ethical concerns that can arise in the regulated arena of medical genetic testing, it is also useful to have students investigate the very different world of online genetic testing. A quick Google search for "genetic testing" will show them how easy it is to get information on certain markers; it is only a matter of some saliva or cheek cells and a few hundred dollars. For example, 23andMe claims to give your genotype at markers, including two linked to breast cancer (reading the details, these are not *BRCA1* or *BRCA2*—https://www.23andme.com/). It is interesting for students to consider how useful the results of these tests can be and what use is implied in the marketing of the tests? At present, the markers tested have very low predictive power but this situation will change rapidly as more alleles linked to "undesirable" conditions are elucidated. It has been shown that different people (personalities, ethnic backgrounds, family situations) respond very differently to risk information (Geller *et al.*, 1997). Should we regulate companies marketing genetic testing and, if so, how?

F. Genetic testing: A simulation

Simulation of genetic testing in the classroom provides an opportunity for students to reflect on the issues associated with genetic testing. This module can be accomplished in a single class meeting or expanded to include more extensive work during the semester. A wide range of genetic tests is available for simulation (http://www.myriadtests.com/inherited.htm). The module described here is designed to increase student awareness of risk for skin cancer. Online information about a test kit available from Myriad Genetics describes "Melaris", a test to determine risk for hereditary melanoma. Relevant material includes (1) Family ties and melanoma, (2) Does melanoma run in your family? (3) Inheriting a gene mutation puts you at higher risk, (4) Melaris, a test for hereditary melanoma, (5) Keeping your skin healthy, (6) Some frequently asked questions, and (7) Family history questionnaire. Each student is asked to read the brochure in class, and draft a fictional narrative based on the information distributed as part of the Melaris test kit. Students may opt to write a letter from a cancer patient to the physician explaining the decision to be tested or the decision not

to be tested. Alternatively, the letter might represent the effort of a cancer patient to inform family members about the testing option and/or hypothetical testing results. This module can be supplemented with Web-based discovery of (1) genetic testing forms for informed consent and (2) state regulations about informed consent practice and procedures associated with genetic testing.

This module can be expanded to include coverage of the roles of The American Academy of Dermatology (http://www.skincarephysicians.com), the American Cancer Society (http://www.cancer.org), The Melanoma Center (http://www.melanomacenter.org/index.html), The National Cancer Institute (http://www.cancer.gov), and The National Society of Genetic Counselors (http://www.ngsc.org).

The simulation exercise can be followed by assignment of specific genetics tests to each of a number of small groups of students. Student groups can present, for example, scenarios involving a test for Huntington disease, breast cancer, or colon cancer. Alternatively, individual writing assignments can be designed to include a wide range of human diseases for which genetic testing is possible (Pagan, 2006).

Discussions of medical genetic testing regularly highlight concerns about the privacy of the information and whether other parties (employer, insurance agent, college admissions officer, potential personal or business partners) can get access to the information (Geller, 1998; Miller; 1998). Two useful videos to illustrate these points are "Do You Really Want to Know?" (CBS video, 1996) and "Bloodlines: Technology Hits Home" (Backbone Media, 2003) and either can form a basis for consideration of the following group exercise. Have students assume they are on a government subcommittee drafting regulations on genetic testing in the workplace.

1. What harm(s) are you trying to prevent occurring with these regulations?
2. What type of regulation is most appropriate? How would it be enforced?

In order for the regulations to stand up to legal challenge, you will have to be careful to define your terms. What is a genetic test? Are the newborn tests for metabolic diseases like PKU genetic? Is information about an actual genetic disease a retroactive genetic test? Could measuring height be a "genetic test" for dwarfism?

After they have addressed these questions introduce the current regulations—Health Insurance Portability and Accountability Act (HIPAA—http://www.hipaa.org/) and the Genetic Information Nondiscrimination Act (GINA—http://www.opencongress.org/bill/110-h493/show, http://www.geneticfairness.org/ginaresource.html), which became law in May, 2008, and critiques of the power and scope of these laws (Sobel, 2007). It is important to bring students to understand that we will not know the degree of protection afforded by these laws until they are tested in the courts.

G. Gene therapy and genetic enhancement

Much of the justification for the high levels of funding for the HGP was based on the potential for improvements in human health. At one level, once scientists understand the underlying mechanism of a genetic disease then it is, theoretically, much easier to design a cure. Substantial progress has been achieved on simple inherited diseases. For example, targeted therapies for cystic fibrosis are now designed with the knowledge that the underlying cause of all the symptoms is a defect in cellular chloride transport. While therapies based on an understanding of the genetic basis of a disease have not often been as successful as predicted, there is no opposition to this type of research. However, once the genetic basis for a disease is understood the potential for a genetic "cure" in the form of gene therapy or "improvement" in the form of genetic enhancement becomes apparent.

The checkered history of the promise and perils of somatic gene therapy to attempt to cure a genetic disease can be used to underscore for students how complex the physiology of multicellular organisms is and how hard simple cures are. Important topics for discussion include: why somatic gene therapy is only applicable to recessive disorders; use of vectors to target genes into cells and the related safety problems; regulation of experimentation on human subjects and informed consent. These can be focused around particular cases, for example, the attempts at gene therapy to cure adenine deaminase deficiency (ADA) in children suffering from Severe Combined Immune Deficiency Syndrome (SCIDS) which resulted in some children being later affected with clonal lymphoproliferative disorder, or the Jesse Gelsinger tragedy where 18-year-old Jesse died as a result of systemic inflammatory response syndrome during a gene therapy clinical trial (McCabe and McCabe, 2008). It is also important to emphasize to students that some of the diseases for which gene therapy was/is under development are extremely debilitating and affected children are suffering profoundly. That parents and doctors are aggressively pursuing any avenue for a cure is not surprising and their position should be carefully considered when evaluating somatic gene therapy's potential. However, somatic gene therapy is essentially under a moratorium at present while safety issues around vector choice and genome integration of inserted genes are addressed.

The inadequacies and dangers of somatic gene therapy suggest that it may never be a very useful method of treating inherited diseases, and two other mechanisms of decreasing the number of individuals affected with these diseases seem far more promising. We can either prevent affected individuals being born, through either embryo or fetus screening, or "fix" the early embryo through germline genetic engineering. There are multiple mechanisms currently practiced where the human embryo that is allowed to develop into a baby is selected in certain ways. Most commonly, amniocentesis and karyotyping fetal chromosomes allow the identification of fetuses with visible chromosomal abnormalities;

this allows the parents to abort that fetus. Students should consider—is prenatal genetic testing—given that many parents elect abortion if a genetic abnormality is detected—eugenics (Duster, 2003, Rifkin, 1998)? There are many interesting perspectives on this argument in the DNA: Pandora's Box video, which features parents of a child with Down Syndrome and Dr. Kay Jamieson arguing against selective abortion of children with disabilities.

Parents who are known to be carriers for a sex-linked recessive genetic disease can elect to use sperm sex sorting or *in vitro* implantation of only female embryos to ensure that they will not have an affected boy. Furthermore, the technologies developed for *in vitro* fertilization and "test-tube" babies allow for more sophisticated screening for traits. Fertilized embryos are allowed to develop to the 8-cell stage and one or two cells removed for genetic analysis. Using polymerase chain reaction (PCR) amplification of small segments of the genome, a geneticist can determine the presence of alleles associated with increased risk of a particular disorder or disease. Thus, parents can decide whether to implant a particular embryo based on the presence/absence of certain markers. When the markers screened for result in a serious genetic disease, there is no doubt that this is a very desirable strategy. It decreases the prevalence of suffering due to genetic diseases without abortion, it allows for sensible choice of the embryos for implantation—a great benefit to all concerned.

While the advantages of preimplantation screening are obvious, students are usually quick to point out two developments from these procedures that are more troubling. Firstly, if it becomes normal procedure to test for diseases, disorders, and traits that are linked to known genetic markers then which diseases, disorders, and traits are worth testing for and screening against? Students have to address the "slippery slope" arguments—after all if we are just screening embryos and choosing a few for implantation why not use the "best" as shown in *GATTACA* (Columbia, 1997). Secondly, genetically screened early embryos would be the perfect precursor for genetic enhancement where extra copies of "beneficial" genes are injected into the embryo to "improve" it. There is an excellent segment in DNA: Pandora's Box where Mario Capecchi discusses his work on artificial chromosomes in mice and then speculates about introducing extra chromosomes containing genes that can be turned on or off at will into human embryos. In that same video, they can see James Watson expressing some of his most controversial eugenic views: "People say it would be terrible if we made all girls pretty. I think it would be great." Student understanding of the issues involved can be expanded by assigning readings pro- (Caplan, 2004; Watson, 2004) and anti- (Fukuyama, 2002; McKibben, 2003; Sandel, 2004) genetic enhancement. This area is very rich in controversial topics for discussion. Can we even discuss the possibility of "genetic basis" of violence and/or risk-taking behavior without eugenic undertones (Hamer and Copeland, 1999; Rifkin, 1998)? Can we imagine a "posthuman future" where genetic enhancement is the norm (Fukuyama, 2002; *GATTACA*,

1997; McKibben, 2003)? Do you still have "free will" if you are programmed to have particular abilities (McKibben, 2003)? Can there still be democracy when people are "preprogrammed" (Fukuyama, 2002)?

H. Careful communication

Communication of complex scientific ideas and experiments to a general audience is probably one of the most challenging aspects of a scientist's responsibilities. It is one for which we are poorly trained, and few of us have the rare gift of making science clear and exciting to a general audience. Articles and editorials in journals like *Science* and *Nature* regularly exhort members of the scientific community to communicate clearly with a broad audience and to invest in public education, while bemoaning the low priority given this skill. Clear concise summaries of new developments in research are particularly important when the topic under discussion has implications on social attitudes and practices. Many advances in genetics are pertinent to fundamental issues of human identity and the privilege given to scientific knowledge makes the careful dissemination of new developments all the more critical. Unfortunately, the need for conservative publication of a project may be in opposition to a very natural tendency for authors of exciting papers to make their papers accessible to a wider audience by adding a little human interest speculation to their discussion. The pitfalls of this approach are vividly illustrated in this exercise in science communication.

Distribute three articles to different groups of students.

1. Evidence from Turner's Syndrome of an imprinted X-linked locus affecting cognitive function (Skuse *et al.*, 1997)
2. A father's imprint on his daughter's thinking (McGuffin and Scourfield, 1997)
3. Genetic X-factor explains why boys will be boys (Highland, 1997)

These articles each describe the same research but are intended for different audiences. The first, a "normal" journal article reports experiments on the intelligence and social aptitude of individuals with Turner's Syndrome and compares those in whom the single X chromosome is inherited from the father with those whose X is maternally inherited. They conclude that children who inherited their single X-chromosome from their mother have a higher incidence of social difficulties despite having normal intelligence levels. This paper ends with the provocative sentence "Our data on normally developing children suggest it (imprinted gene on X-chromosome) may also exert an effect on social and cognitive abilities in the normal range." The *Nature* News and Views article in the same issue presents this paper for the general scientific audience. It generalizes and builds upon the Skuse article to present a case for the molecular basis of behavior that is gender-linked: "Now, for the first time, we have evidence about

the location of a gene that plays a part in behavioral sexual dimorphism." This research was reported in the popular press (The Telegraph is a national newspaper in the UK) in the following terms "Men are born lacking a factor responsible for female intuition and social graces, says a study that reveals the first genetic basis for differences in the way that men and women behave" and continues with a series of sexist comments about undermining the trend toward sexual equality! (Highland, 1997).

One effective approach is to assign each of the articles to a group of students, have them discuss it in class, decide what they think they know from the article and what evidence there is to support their conclusions. They can then present their article to the whole group so that everyone can see how the progression of the "translation" of research for the general audience can lead to serious misrepresentation of the research. They should see that this occurs through a series of incremental changes in the meaning of the "conclusion" of the research article and tends to result from the journalists' attempts to make the article more understandable and more appealing. An important question to discuss is who, if anyone, is at fault in this case and what are the responsibilities of the scientists to prevent their research being misused in someone's social agenda.

Another pedagogical approach to achieve the same end is to charge individual students to work as investigative reporters to track down a specific primary literature article cited in a current press release found online, in a newspaper article or on broadcast television, and present the results of the investigation to the class. The scope of the problem of misrepresentation of scientific evidence in the media becomes apparent, when the class as a whole subsequently reviews the collection of articles. The discovery of misleading or sensationalized information in the media is enlightening and generates a healthy skepticism in the students.

I. Analysis of relevant fiction and media

Fiction engages student interest and is accessible to students with a broad range of backgrounds. Students can identify societal issues related to genetics by analyzing fiction and by studying the research process described by novelists. In this section, we provide examples of recent work by two novelists, Jodi Picoult and Lori Andrews. Online access to Web sites maintained by Picoult (http://www.jodipicoult.com) and Andrews (http://www.kentlaw.edu/faculty/landrews/) permits students to become acquainted with the authors and to explore the background and impact of specific novels by these authors.

Research into Vermont's eugenics project of the 1920s and 1930s was conducted by Jodi Picoult in preparation for her novel, *Second Glance* (Picoult, 2003); stem cell research and "designer babies" are issues addressed in her

subsequent novel, *My Sister's Keeper* (Picoult, 2004). Teaching *My Sister's Keeper* in the undergraduate curriculum has been described in detail by Terrance McConnell (2008).

Lori Andrews is the author of three mysteries involving a fictional geneticist: *Sequence* (Andrews, 2006), *The Silent Assassin* (Andrews, 2007), and *Immunity* (Andrews, 2008). After reading and discussing one or more of these novels, students can discover a direct connection between fiction and fact, by reading nonfiction work by Andrews. Andrews is coauthor of a law school casebook (Mehlman, 2006), which documents cases relevant to genetics.

The casebook is divided into four sections. The first provides an introduction to the context in which decisions about genetics have been made. The second section covers genetic research, including issues related to federal and international regulations, intellectual property rights, and research initiatives such as the Human Genome Diversity Project and the Environmental Genome Project. The third section deals with medical applications of genetics, including prenatal testing and gene therapy. The fourth section addresses the nonmedical application of genetics, including paternity testing, and the use of genetic technologies by social institutions, including law enforcement officials, courts, insurers, employers, and schools. Individual chapters from the textbook can be assigned to small groups of students who select specific cases to dramatize for the class. For example, one student group may present a mock courtroom scene based on one or two specific patent law cases described in Chapter 5, Commercialization of Genetic Research: Property, Patents, and Conflicts of Interest. Another student group may engage in similar role-play to present a family court drama based on liability for malpractice in prenatal screening from Chapter 6, Genetic Testing and Reproduction. Students also may prefer to debate issues raised in particular cases, presenting the debate as a mock radio or television broadcast. Explicit connections between a factual case and the issues raised in one of the assigned novels can be utilized to conclude this module. In *Ferrell versus Rosenbaum* (Mehlman, 2006, p. 364), a case involving conception of a sibling to be a donor, students discover a case similar to those encountered by Jodi Picoult in her research for *My Sister's Keeper* (Picoult, 2004). Alternatively, study of individual court cases can also be organized in the context of individual writing assignments. For example, the casebook, *Andrews' Genetics: Ethics, Law and Policy*, second edition, includes detailed coverage of 36 principal cases among the 100 cases cited and discussed (Mehlman *et al.*, 2006).

Additional resources available to faculty and students for use in this, or any of the other modules, include current press reports, commercial, and educational video productions. Students can expect to find current press about genetic advances regularly in the *New York Times*, particularly in the Science Times section and Style magazine. A Pulitzer Prize-winning series, The DNA Age, by Amy Harmon is also available online from the *New York Times* (http://topics.

nytimes.com/top/news/national/series/dnaage/index.html). The frequent availability of late-breaking news from these sources improves student awareness of the rapid pace of genetic advances. It is useful to ask the students to share press releases from other online, broadcast or print news sources with the class for regular discussion of ELSI issues raised by these advances. Catalogs of educational video productions are available from the Howard Hughes Medical Institute (http://www.holidaylectures.org). For example, the 2002 lecture set entitled Scanning Life's Matrix: Genes, Proteins, and Small Molecules includes two lectures by Eric Lander covering genetic advances, comparative genomics, and genetic variation. Use of this material in a nonmajors course effectively provides expert guest lectures to supplement course material. Useful videos can also be purchased from Films for the Sciences and Humanities (http://www.films.com). Additional film resources are described in Sections II.A, II.B, II.F, and II.G.

III. STRATEGIES

A. Integration of ELSI issues into nonmajors courses

Many undergraduate institutions offer nonmajors topics courses, some as part of distribution or seminar programs but all with the goal of providing a broad education to their students. These courses offer unique opportunities to teach about human genetics and its consequences to a broad spectrum of students; however, they also provide substantial challenges as an instructor may be required to find common ground among students with no college-level science preparation and those currently enrolled in sophomore-level college Biology and Chemistry coursework. Each of the authors teaches one of these ELSI courses at their home institutions in typical one semester 3 h/week format.

The goal of Genetic Testing, the ELSI course taught by K.L.T., is to examine genetic testing from a variety of scientific and societal perspectives. The context for the course is the natural world, in which all living creatures share the universal language encoded in DNA. The focus of the course is the DNA fingerprint, a genetic test that can be applied to DNA from any organism. The class is divided into groups of no more than five students, when group work is appropriate. The instructor divides students into groups to guarantee that each group includes at least one student with a strong college-level science background. For example, a group ideally might include a premedical student, a prelaw student, a student majoring in business, a student majoring in the arts, and a student majoring in the social sciences. Group work includes planning sessions during and outside class time to prepare for group oral presentations. Typically students elect to divide the presentation of material by

roles to be played in a mock trial, radio or television broadcast, or by debating teams. Groups are challenged to present as many different perspectives on a particular issue as possible. Within a group, students are also challenged to advocate for a position that does not necessarily reflect their own personal point of view.

The semester begins with the introduction of DNA fingerprint technology in the context of current studies in human ancestry and evolution (see Section II.B). Next, group work focused on DNA biobanks culminates in class presentations. In parallel, written responses to weekly reading assignments about evolution are collected from students individually. Preparation for a second round of group class presentations covering the use of DNA fingerprint technology in medical diagnostics (see Section II.D) follows simulation of a medical genetic test in the classroom (see Section II.F). The second half of the semester is devoted to a deeper investigation of ELSI issues based on relevant fiction, media, and court cases (see Section II.I). The final project for the course is a significant paper challenging each student to demonstrate their ability to communicate results and implications of a unique genetic study based on information from a wide range of sources, including a primary literature reference and press releases about that work available from the popular press.

J.M.G. teaches a Genetics and Society course, which focuses on genetic determinism and issues of human identity. This course evolved from an interdisciplinary seminar, which was co-taught with a philosopher, and interdisciplinarity is a common denominator for the following examples of courses that also could be adapted to courses for nonmajors. Beecher-Monas (2008) has described a law school seminar course, Genetics and Law, on future dangerousness predictions in the courts. Students explore genetic predictions for violent behavior, material that could be adapted for an interdisciplinary general education course based in psychology and sociology. Segady (2008) has described an interdisciplinary course based in bioethics and sociology, Ethical Futures: Implications of the Human Genome Project, which could be also adapted for a general education curriculum. Stober and Yarri (2008) developed a team-taught course, God, Science, and Designer Genes, integrating the disciplines of biology and Christian theology, which was designed to fulfill either general education biology or ethics requirements.

B. Integration of ELSI issues into genetics courses for bioscience majors

In a recent survey of professors teaching undergraduate genetics courses, most believed that it is very important to include the teaching of ELSI issues in their courses (Booth and Garrett, 2004). However, these same instructors almost unanimously indicated they had insufficient time to adequately cover ELSI issues

in their courses. Thus, it is very important to devise mechanisms of integrating ELSI discussions into regular coursework with minimal loss of the "core" material. This works best when the ELSI topic is closely aligned with the syllabus. As discussed earlier, the module on eugenics fits well into the first weeks of a genetics course when Mendelian and classical human genetics are discussed. One or more of the genetic testing modules can be incorporated as the class learns about the techniques of molecular biology and explores the potential of genomics. One way of avoiding the loss of class time is to utilize lab time. For example, if the students are running a genetic testing laboratory exercise (e.g., microsatellite analysis of cheek cell DNA) then one lab period could be spent isolating DNA, setting up the PCR and watching one of the videos about ELSI issues arising from genetic testing. During the next laboratory, they can discuss an ELSI topic while the gel of their PCR samples is running. It is particularly beneficial for them to discuss the applications and implications of a technology at the same time as they directly experiencing the challenges of getting good results themselves.

Another approach involves the assignment of "new" College ID cards simulating a time (in the not-too-distant future) when individual genomes can be readily analyzed and/or sequenced so that particulars of an individual's genome are present on the card. This "information" can take a variety of forms and be used in several ways. Students assigned high risk for a disease or trait can consider how this information is useful in terms of prevention/family planning, etc. or whether the knowledge negatively impacts their self-image. Or students who "discover" that they have been genetically enhanced with extra DNA realize the potential of preimplantation genetic enhancement. The genetic identity card approach gives the advantage of focusing the students on a "real" situation. When in a hypothetical discussion most students tend to reject enhancement as too freakish. However, once they realize that they "know" that they have an increased risk of colon cancer or early memory loss and dementia, they start to want to do something about it. And, when there is the possibility of a genetic improvement (e.g., an artificial chromosome with extra "good" copies of *HNPCC1* to decrease the likelihood of cancer), then they start to waiver. If the class is deliberately engineered where some of them have genetic enhancement chromosomes and others do not, the discussion usually becomes pro-enhancement because, in our competitive society, everyone wants full access to what is available, exactly the genetic one-upmanship discussed by McKibben in his book criticizing these technologies, *Enough* (McKibben, 2003).

The genetic identity card can be used in many ways. It can form the foundation for an entire nonmajors general education course (Section II.A) in genetic testing and determinism. Or a card can be used to generate outside class discussion among bioscience majors and their nonscience peers. For example,

students who have cards could lead a discussion at a student club meeting or after the showing of a futuristic film, for example, *GATTACA*. Thus majors are encouraged to both engage the ELSI issues arising from their studies and enhance their communication skills with the "public," both highly desirable outcomes for our future scientists.

IV. CONCLUDING REMARKS

The application of science and technology in society often leads to important and controversial decisions that must be resolved by both scientists and the public. Among the decisions that have been/are being made are those that have the potential to fundamentally alter life as we know it. For example, nuclear technology with its potential to provide massive amounts of cheap energy, which is accompanied by potential for intentional (weapons) or unintentional (accidents) destruction, has been a source of controversy for decades. Mishandled or misregulated, nuclear technologies clearly have the potential for catastrophe. Less dramatic, but no less fundamentally serious, is the rate of degradation of the natural environment and the vexing problems of balancing human development with preservation of the natural world. The emerging technologies in genetics and neuroscience also have the potential to alter humanity in fundamental ways we are only just beginning to address (Fukuyama, 2002; McKibben, 2003). It is very important that we educate students to become scientifically literate citizens, to give them the knowledge and understanding they need to engage effectively in discussions, debates, and decision-making involving science in their personal and professional lives, and to help them appreciate science and the roles it plays in modern society. The resources and strategies presented in this chapter for teaching ELSI issues that arise in modern genetics are designed to aid in accomplishing this goal throughout the undergraduate curriculum.

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