Name______________________________

Genes

Genetic engineering has provoked controversy across the globe. Some people argue that such activity manipulates nature and poses serious threats to humanity. Others, however, believe that genetic engineering offers boundless and unforeseen benefits to humanity. What should be the limits of genetic engineering?

Check off as you complete the Summaries:

____Source A

____Source B

____Source C

____Source D

____Source E

____Source F

____Additional Source

____Additional Source

Source A (Wright)

Wright, Robert. "Who Gets the Good Genes?" *Time*, Jan. 11, 1999.

The following is an essay from a weekly news magazine.

In the 1932 novel *Brave New World*, Aldous Huxley envisioned future childbirth as a very orderly affair. At the Central London Hatchery and Conditioning Center, in accordance with orders from the Social Predestination Room, eggs were fertilized, bottled and put on a conveyor belt. Nine months later, the embryos—after "decanting"—were babies. Thanks to state-sponsored brainwashing, they would grow up delighted with their genetically assigned social roles—from clever, ambitious alphas to dim-witted epsilons.

Ever since publication of Huxley's dystopian novel, this has been the standard eugenics nightmare: government social engineers subverting individual reproductive choice for the sake of an eerie social efficiency. But as the age of genetic engineering dawns, the more plausible nightmare is roughly the opposite: that a laissez-faire eugenics will emerge from the free choices of millions of parents. Indeed, the only way to avoid Huxleyesque social stratification may be for the government to get into the eugenics business.

Huxley's scenario made sense back in 1932. Some American states were forcibly sterilizing the "feebleminded," and Hitler had praised these policies in *Mein Kampf*. But the biotech revolution that Huxley dimly foresaw has turned the logic of eugenics inside out. It lets parents choose genetic traits, whether by selective abortion, selective reimplanting of eggs fertilized in vitro or—in perhaps just a few years—injecting genes into fertilized eggs. In Huxley's day eugenics happened only by government mandate; now it will take government mandate—a ban on genetic tinkering—to prevent it.

An out-and-out ban isn't in the cards, though. Who would try to stop parents from ensuring that their child doesn't have hemophilia? And once some treatments are allowed, deciding where to draw the line becomes difficult.

The Bishop of Edinburgh tried. After overseeing a British Medical Association study on bioethics, he embraced genetic tinkering for "medical reasons," while denouncing the "Frankenstein idea" of making "designer babies" with good looks and a high IQ. But what is the difference? Therapists consider learning disabilities to be medical problems, and if we find a way to diagnose and remedy them before birth, we'll be raising scores on IQ tests. Should we tell parents they can't do that, that the state has decided they must have a child with dyslexia? Minor memory flaws? Below-average verbal skills? At some point you cross the line between handicap and inconvenience, but people will disagree about where.

If the government does try to ban certain eugenic maneuvers, some rich parents will visit clinics in more permissive nations, then come home to bear their tip-top children. (Already, British parents have traveled to Saudi Arabia to choose their baby's sex in vitro, a procedure that is illegal at home.) Even without a ban, it will be upper-class parents who can afford pricey genetic technologies. Children who would in any event go to the finest doctors and schools will get an even bigger head start on health and achievement.

This unequal access won't bring a rigid caste system a la *Brave New World*. The interplay between genes and environment is too complex to permit the easy fine-tuning of mind and spirit. Besides, in vitro fertilization is nobody's idea of a good time; even many affluent parents will forgo painful invasive procedures unless horrible hereditary defects are at stake. But the technology will become more powerful and user friendly. Sooner or later, as the most glaring genetic liabilities drift toward the bottom of the socioeconomic scale, we will see a biological stratification vivid enough to mock American values.

Enter the government. The one realistic way to avoid this nightmare is to ensure that poor people will be able to afford the same technologies that the rich are using. Put that way, it sounds innocent, but critics will rightly say it amounts to subsidizing eugenics.

State involvement will create a vast bioethical quagmire. Even if everyone magically agrees that improving a child's memory is as valid as avoiding dyslexia, there will still be things taxpayers aren't ready to pay for—genes of unproven benefit, say, or alterations whose downsides may exceed the upside. (The tendency of genes to have more than one effect—pleiotropy—seems to be the rule, not the exception.) The question will be which techniques are beyond the pale. The answers will change as knowledge advances, but the arguments will never end.

In *Brave New World*, state-sponsored eugenics was part of a larger totalitarianism, a cultural war against family bonds and enduring romance and other quaint vestiges of free reproductive choice. The novel worked; it left readers thinking that nothing could be more ghastly than having government get into the designer-baby business. But if this business is left to the marketplace, we may see that government involvement, however messy, however creepy, is not the creepiest alternative.

Discourse Activity

1) Wright presents his claim in the last sentence of paragraph two. State Wright's claim in your own words.

2) Wright points out the possible "nightmare" of government involvement in genetic engineering, yet argues for its necessity. What assumptions does he make?

3) Wright's concluding sentence intends to startle and generate an emotional appeal. What does Wright expect his audience to consider in his conclusion?

4) Those who agree with Wright would say ________.

5) Those who oppose Wright's claim would say ________.

Source B (Cohen)

Cohen, Eric. "The Real Meaning of Genetics." *The New Atlantis* 9 (Summer 2005).

The following passage is an excerpt from a journal that regularly considers the relationship between technology and society.

Possibility and Prediction

In thinking about the new genetics, we seem to commit two errors at once: worrying too much too early and worrying too little too late. For decades, scientists and science-fiction writers—and it is sometimes hard to tell the difference—have predicted the coming of genetic engineering: some with fear and loathing, some with anticipatory glee. But when the gradual pace of technological change does not seem as wonderful as the dream or as terrible as the nightmare, we get used to our new powers all too readily. Profound change quickly seems prosaic, because we measure it against the world we imagined instead of the world we truly have. Our technological advances—including those that require overriding existing moral boundaries—quickly seem insufficient, because the human desire for perfect control and perfect happiness is insatiable.

Of course, sometimes we face the opposite problem: Scientists assure us that today's breakthrough will not lead to tomorrow's nightmare. They tell us that what we want (like cures for disease) is just over the horizon, but that what we fear (like human cloning) is technologically impossible. The case of human cloning is indeed instructive, revealing the dangers of both over-prediction and under-prediction. So permit me a brief historical digression, but a digression with a point.

In the 1970s, as the first human embryos were being produced outside the human body, many critics treated in vitro fertilization and human cloning as equally pregnant developments, with genetic engineering lurking not far behind. James Watson testified before the United States Congress in 1971, declaring that we must pass laws about cloning now before it is too late. In one sense, perhaps, the oracles were right: Even if human cloning did not come as fast as they expected, it is coming and probably coming soon. But because we worried so much more about human cloning even then, test-tube babies came to seem prosaic very quickly, in part because they were not clones and in part because the babies themselves were such a blessing. We barely paused to consider the strangeness of originating human life in the laboratory; of beholding, with human eyes, our own human origins; of suspending nascent human life in the freezer; of further separating procreation from sex. Of course, IVF has been a great gift for many infertile couples. It has answered the biblical Hannah's cry, and fulfilled time and again the longing most individuals and couples possess to have a child of their own, flesh of their own flesh. But it has also created strange new prospects, including the novel possibility of giving birth to another couple's child—flesh not of my flesh, you might say—and the possibility of picking-and-choosing human embryos for life or death based on their genetic characteristics. It has also left us the tragic question of deciding what we owe the thousands of embryos now left-over in freezers—a dilemma with no satisfying moral answer.

But this is only the first part of the cloning story. Fast-forward now to the 1980s. By then, IVF had become normal, while many leading scientists assured the world that mammals could never be cloned. Ian Wilmut and his team in Scotland proved them all wrong with the birth of Dolly in 1996, and something similar seems to be happening now with primate and human cloning. In 2002, Gerald Schatten, a cloning researcher at the University of Pittsburgh, said "primate cloning, including human cloning, will not be in our lifetimes." By 2003, he was saying that "given enough time and materials, we may discover how to make it work." And by 2005, Schatten and his South Korean colleagues had reliably cloned human embryos to the blastocyst stage, the very biological moment when they might be implanted to initiate a pregnancy. In all likelihood, the age of human reproductive cloning is not far off, even if the age of full-blown genetic engineering may never come.

Looking at where the science of genetics is heading, we must beware the twin vices of over-prediction and under-prediction. Over-prediction risks blinding us to the significance of present realities, by inebriating us with distant dreams and distant nightmares. Under-prediction risks blinding us to where today's technological breakthroughs may lead, both for better and for worse. Prediction requires the right kind of caution—caution about letting our imaginations run wild, and caution about letting science proceed without limits, because we falsely assume that it is always innocent and always will be. To think clearly, therefore, we must put aside the grand dreams and great nightmares of the genetic future to consider the moral meaning of the genetic present—the meaning of what we can do now and why we do it. And we need to explore what these new genetic possibilities might mean for how we live, what we value, and how we treat one another.

Humanly speaking, the new genetics seems to have five dimensions or meanings: (1) genetics as a route to self-understanding, a way of knowing ourselves; (2) genetics as a route to new medical therapies, a way of curing ourselves; (3) genetics as a potential tool for human re-engineering, a prospect I find far-fetched; (4) genetics as a means of knowing something about our biological destiny, about our health and sickness in the future; and (5) genetics as a tool for screening the traits of the next generation, for choosing some lives and rejecting others. I want to explore each of these five dimensions in turn—beginning with the hunger for self-understanding.

Discourse Activity

1) Cohen's thesis asks his audience to consider the dangers of our desire for perfection. State Cohen's claim in your own words.

2) In paragraph six Cohen urges us to consider specific questions about "the new genetics." Consider the importance of each dimension, and its positive or negative impact on society.

3) With what position does Cohen assume some will agree?

4) What might be said in opposition to Cohen's views?

Source C (Adey)

Adey, Bryant. http://www.cartoonstock.com/blowup.asp?imageref=abr0015&artist=Bryant%2C+Adey&add=inbasket&help=.

The following cartoon offers several comments about genetic engineering.

"I hope there's nothing genetically modified in this"

Discourse Activity

1) Characterize your initial response to the cartoon. What features prompt your response?

2) What argument does this text make about the issues of genetic engineering?

3) How is that argument conveyed?

4) How does this cartoon connect to the other sources in this collection?

Source D (McElroy)

McElroy, Wendy. "Victims from Birth." April 9, 2002. http://www.ifeminists.com/introduction/editorials/2002/0409.html.

The following essay is an online commentary that explores issues of personal responsibility in connection with scientific developments.

When Sharon Duchesneau gave birth on Thanksgiving Day to a deaf son, she was delighted.

Duchesneau and her lesbian partner, Candace McCullough, had done everything they could to ensure that Gauvin would be born without hearing. The two deaf women selected their sperm donor on the basis of his family history of deafness in order, as McCullough explained, "to increase our chances of having a baby who is deaf."

So they consciously attempted to create a major sensory defect in their child.

Scientists and philosophers have been debating the morality of new reproductive technologies that may allow us to design "perfect" human beings. Advocates dream of eliminating conditions such as spina bifida; critics invoke images of Nazis creating an Aryan race.

But what of prospective parents who deliberately engineer a genetic defect into their offspring?

Why? Duchesneau illustrates one motive.

She believes deafness is a culture, not a disability. A deaf lifestyle is a choice she wishes to make for her son and his older sister Jehanne. McCullough said she and her partner are merely expressing the natural tendency to want children "like them."

"You know, black people have harder lives," she said. "Why shouldn't parents be able to go ahead and pick a black donor if that's what they want?"

Passing over the problem of equating race with a genetic defect, McCullough seems to be saying that deafness is a minority birthright to be passed on proudly from parent to child. By implications, those appalled by their choice are compared to bigots.

Some in the media have implicitly endorsed their view.

On March 31st, the Washington Post Magazine ran a sympathetic cover story entitled "A World of Their Own" with the subtitle, "In the eyes of his parents, If Gauvin Hughes McCullough turns out to be deaf, that will be just perfect." The article features Gauvin's birth and ends with the two women taking him home. There they tell family and friends that, "He is not as profoundly deaf as Jehanne, but is quite deaf. Deaf enough." The article does not comment critically on the parents' decision not to fit Gauvin with a hearing aid and develop whatever hearing ability exists.

The Duchesneau case is particularly troubling to advocates of parental rights against governmental intrusion. The moral outrage it elicits easily can lead to bad law – laws that may hinder responsible parents from using genetic techniques to remedy conditions such as cystic fibrosis in embryos. Selective breeding, after all, is a form of genetic engineering. The Duchesses case, then, brings all other forms of genetic engineering into question.

The championing of deafness as a cultural "good" owes much to political correctness or the politics of victim-hood, which view group identity as the foundation of all political and cultural analysis.

Disabled people used to announce, "I am not my disability." They demanded that society look beyond the withered arm, a clubbed-foot, or a wheel chair and see the human being, a human who was essentially identical to everyone else.

Now, for some, the announcement has become, "I am my deafness. That is what is special about me."

Society is brutal to those who are different. I know. As a result of my grandmother contracting German measles, my mother was born with a severely deformed arm. She concealed her arm beneath sweaters with sleeves that dangled loosely, even in sweltering weather. She hid.

Embracing a physical defect, as Duchesneau and McCullough have done, may be a more healthy personal response. Certainly they should be applauded for moving beyond the painful deaf childhoods they describe.

However, I remember my mother telling me that the birth of her children—both healthy and physically unremarkable—were the two happiest moments of her life. I contrast this with Duchesneau who, knowing the pain of growing up deaf, did what she could to impose deafness upon her son.

Deafness is not fundamentally a cultural choice, although a culture has sprung up around it. If it were, deafness would not be included in the Americans with Disabilities Act—a source of protection and funding that deaf-culture zealots do not rush to renounce.

But if deafness is to be considered a cultural choice, let it be the choice of the child, not the parents. Let a child with all five senses decide to renounce or relinquish one of them in order to embrace what may be a richer life. If a child is rendered incapable of deciding "yes" or "no," then in what manner is it a choice?

Discourse Activity

1) Determine McElroy's position on this issue.

2) What questions would you ask the Duchesneaus? Speculate about their answers.

3) What questions would you ask McElroy? Speculate about her answers.

4) Complete the following statement. While some would agree that ______, many will say that ______.

Source E (Hinxton Group)

The Hinxton Group, An International Consortium on Stem Cells, Ethics and Law
Consensus Statement, February 24, 2006

The following is an excerpt from the declaration of principles that the above named group recommends for governing the ethical and legal regulation and oversight of stem cell and related research and its clinical applications.

Foreword

Societies have the authority to regulate science, and scientists have a responsibility to obey the law. However, policy makers should refrain from interfering with the freedom of citizens unless good and sufficient justification can be produced for so doing. As scientists, philosophers, bioethicists, lawyers, clinicians, journal editors and regulators involved in this field, we have reached consensus that if humankind is to have the very best chance of realizing the benefits of stem cell research in an ethically acceptable manner, the following principles should govern the ethical and legal regulation and oversight of stem cell and related research and its clinical applications. This is by no means a comprehensive list of principles, but rather a declaration of those discussed and agreed upon by our group:

1. Stem cell research should seek to minimize harm, and any risk of harm should be commensurate with expected overall benefit. Scientists and clinicians should conduct research according to ethically acceptable norms. For example, research should be conducted so as to protect the well-being, liberty and rights of cell and tissue donors as well as research participants. Research participants and donors of human materials must provide valid informed consent, and conflicts of interest should be appropriately addressed.

2. The law carries great power to facilitate or restrict scientific exploration in the area of stem cell research. Law makers should be circumspect when regulating science. When enacted, laws or regulations governing science nationally and internationally ought to be flexible, so as to accommodate rapid scientific advance.

3. Scientists and clinicians have a responsibility to obey the law. However, they also have the right to know through clear and explicit laws, what is and is not permitted with respect to their research, the jurisdiction of any prohibitions, and related penalties, so that they can regulate their behavior accordingly.

4. In countries with laws that restrict elements of human embryonic stem cell (hESC) research but that do not expressly prohibit international collaborations, research institutions should neither discriminate against nor restrict the freedom of their investigators who want to travel to do work that is undertaken with scientific and ethical integrity.

5. Law makers should be similarly circumspect in restricting citizens' conduct extraterritorially with regard to stem cell research. So long as scientifically and

ethically defensible hESC research is undertaken in a country in which it is legally permissible, scientists should be free to participate in that research without fear of being liable to prosecution, restriction, or discrimination in another jurisdiction.

6. It is essential that scientists and policy makers consult each other and the public in the attempt to develop regulatory regimes for stem cell research that strike the best possible balance between free scientific inquiry and social values.

7. Journal editors should encourage authors to include in manuscripts explicit descriptions of their roles in the published research so as to clarify the appropriateness of their participation, in particular for researchers residing in countries with more restrictive laws and collaborating with researchers residing in countries with more permissive laws.

Discourse Activity

1) What justification for their declaration does the Hinxton Group offer in the Foreword?

2) On what observations of past experience are these declarations based?

3) State briefly in your own words the primary consideration of each declaration.

4) How do these declarations connect to the others sources in this collection?

5) How do the declarations made by this international consortium suggest the importance of the issues of stem cell research to a global society?

Source F (Rhodes)

Rhodes, Jonathan. "Building a Public Conversation on the Meaning of Genetics." http://www.thehumanfuture.org/commentaries/commentary_rhodes01.html.

The following essay is a Web-based commentary concerning the need for an informed debate about issues associated with genetic research.

Why Should We Care About Genetics?

Town hall meetings are commonplace during election cycles, as politicians roll up their shirtsleeves to get out and meet the people in a community forum. In the spirit of bringing the community together to share ideas, the Illinois Humanities Council (IHC) has commenced a year-long project designed to increase public knowledge of genetics. The initiative, entitled Future Perfect: Conversations on the Meaning of the Genetics Revolution, has been designed to engage citizens in conversations about advances in genetics and their impact on the individual and society. During the kick-off event, the IHC brought together experts and laypersons in an exploration of the basic question: "Why should we care about genetics?"

The Possibility of an Informed Debate

Jon D. Miller, professor of integrative studies at Michigan State University, opened the discussion by setting out the challenges. Chief among them is the difficulty of having an informed public debate on important scientific developments.

Miller framed the issue by asserting that the 20th century was "the century of physics," with Einstein's theories transforming the way we live in and think about the world. He then proclaimed that the 21st century will be "the century of biotechnology," during which scientific developments in biotechnology and nanotechnology will have the same potential to radically shift how we view the world and how we function within it.

During the biotech century, advances in genetics will alter the definition of health. And, over time, as these advances are assimilated into everyday discussions about health and well being, they will become fixtures in the public policy debate.

As the human foray into the 21st century commences, the current landscape of public knowledge, understanding, and engagement must be assessed. Over the past three decades, Miller's research has focused on measuring the general biomedical and genetic literacy in the United States and Europe. In town-hall-meeting spirit, Miller's presentation involved the audience in an interactive dialogue by way of a series of true-false questions testing scientific literacy in the area of genetics.

Two-thirds of the audience received a "passing" score. This "passage rate" was significantly higher than the "passage rate" Miller found in his studies of public scientific literacy. In these studies, Miller found such literacy highest in Denmark, with 47% of the Danish participants "passing." The United States came in at the middling rank of 28th among the 34 countries studied.

Such an outcome, Miller argued, is far too low for a democratic society. Informed debate about genetics or other complex scientific developments cannot occur if citizens do not have a basic understanding of the principles, issues, and terms involved. To achieve this, Miller advocated for a fundamental change in scientific education. The requisite changes include: teaching children the core skill sets - including analysis and critical thinking - that will enable them to grapple with the science and technologies of tomorrow; and offering ongoing, just-in-time, continuing education on science and technology for adults throughout their lifetime.

Taking the Good with the Bad?

Today, however, a classical understanding of genetics may not be sufficient to effectively manage health in a complicated scientific landscape. Rex Chisholm, director of the Center for Genetic Medicine at Northwestern University and the second presenter during the town hall meeting, articulated his belief that the public is ready for a more fully developed understanding of genetics.

According to Chisholm, modern-day genetics likely mean that drugs can be selected for effectiveness based on one's genetic makeup, but this will also likely mean that governments or corporations have access to this most personal information. Such information could lead to discrimination on many fronts. Chisholm asked the audience to consider whether the potential benefits of tailor-made drugs outweigh the potential stigmas.

Art as a Medium for Contemplating Science

Big questions about the role of genetics in public health need to be approached from diverse perspectives across disciplines. Liz Lerman, founding artistic director of the Liz Lerman Dance Exchange and closing speaker, suggested that the arts could serve as a bridge between the complexities of science and culture. In proving of this potential role for the arts, Lerman set out explore genetics through dance and other media. Through her contemporary dance work, entitled Ferocious Beauty: Genome, Lerman studied the effects of genetic disease on the body, including the unique movements of those affected by Huntington's disease.

The key to an informed debate about genetics turns upon understanding, and the key to achieving understanding is recognition of the different ways in which learning occurs. By utilizing novel approaches to learning, the arts can prove enriching in a way that other disciplines are not, according to Lerman. As a result, the arts offer an avenue for cultural exploration and meaningful exchange that is essential to public discourse on genetics and other emerging technologies.

Seizing the Opportunity

When science changes its mind, everyone is affected. And science changes its mind all the time, because that is what science is supposed to do in light of new knowledge. As humanity embarks on what might be a genetics revolution, the ability to improve health will only be matched by the potential for the misuse of the technology. Developments in technology will inevitably cause disruption and change, impacting humankind on an unmatched global scale and in unprecedented, and likely permanent, ways. Thus, prospective and ongoing public discourse about the ethical, legal, societal implications of genetics is essential.

Discourse Activity

1) Rhodes's article is divided into five parts. What are the features of each part?

2) Complete the following statement:
Rhodes presents the idea that __________.

3) What could be expected to follow if others agree with Rhodes?

4) How does Rhodes's presentation connect to the other sources in this collection?
Wright:
Cohen:
Adey cartoon:
MeElroy:
Hinxton Group:

Genes

Activity: Planning Your Essay

After your initial discourse with the sources respond to these follow-up questions. These questions assume you have read and responded to all of the sources.

1) Wright's claim that __________ would most likely appeal to __________ because __________.

2) Cohen's claim based on __________ is important because __________.

3) The Adey cartoon validates the claims of __________ because __________.

4) McElroy's argument questions the morality of __________ because __________.

5) The Hinxton Group declarations create an argument in favor of __________ because __________.

6) Rhodes and the Hinxton Group present ideas that suggest the importance of global discourse because __________.

Complete one of the two following statements.

Although __________, genetic engineering undermines rather than enhances the promise of humanity because __________.

Although __________, genetic engineering enhances rather than undermines the promise of humanity because __________.

Or, write a thesis sentence of your own.

List the sources to which you will refer and cite the main points from each that will support your claim.