GENE THERAPY: PROMISE, PITFALLS, AND ABUSES

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Gene therapy is one of the hot new research areas in biotechnology. The recently completed mapping of the human genome and years of genetic engineering research drive its progress. Genes are the blueprints for proteins, which serve as building blocks for tissues as well as regulators of chemical reactions taking place inside all living cells. Gene errors cause disruptions to their expression and may result in disease. Ordinary medicine can only moderate symptoms of genetic diseases and treatments are typically only temporary. Gene therapy has the potential to eliminate the root causes of certain diseases by repairing or modifying the patient's genetic code. Being able to directly manipulate and correct the root causes of genetic disorders promises to revolutionize treatment, but gene therapy is highly controversial, and so far has not been as successful as anticipated. Critics point to its non-therapeutic enhancement possibilities, the potential for eugenic social policies, and a spotty safety record that resulted in the deaths of subjects undergoing unproven treatments. The pitfalls and abuses typical of new scientific medicines with great potential, but unproven track record, must be avoided in order to earn the support from the government and the public. In order for this revolutionary biotechnology to flourish and finally provide modern medicine with the long awaited jolt from its recent idle state of elective surgeries and countless mood drugs, the direction in which gene therapy evolves must be carefully guided through government and public policy to achieve its potential as the preventative answer to improving the quality of human life.

The pitfalls and abuses of gene therapy can be exposed and highlighted through the concepts presented by Roy Porter in his book *The Greatest Benefit to Mankind.* Porter states that "western scientific medicine has not fully delivered the goods it promised [and] has not proved successful against lethal diseases" (689). Once some of the devastating bacterial and viral diseases of previous centuries were brought under control by conventional medicine, it seems that the progress against the more complex ailments has stalled. In this way, gene therapy is no different. As Gardiner Harris writes in his *New York Times* article "Gene Therapy is Facing a Crucial Hearing," "gene therapy's disappointing history is mirrored in other medical technologies once highly promoted, [and] reaping the fruits of such technological

advances is taking much longer than executives in biotechnology and pharmaceuticals once suggested" (A16). Furthermore, in their article in the *Canadian Medical Association Journal,* Johnston and Baylis harshly typify the pitfalls and abuses of gene therapy as "overestimating the short-term therapeutic potential, exposing participants to serious risk in the face of adverse data, omitting . . . information from informed-consent forms, and having financial conflicts of interest" (1786). Lack of success in addition to alarming abuses raises serious concerns, provides ammunition for the critics, and makes winning the much-needed support among the skeptics an uphill battle.

Not only has gene therapy, in Porter's words, "not fully delivered the goods," it has encouraged the hype of scientific medicine that he describes as "inflated expectations, which the public eagerly swallow[s], yet [as] those expectations become unlimited, they are unfulfillable" (718). Ambitious medical researchers have a tendency to create publicity around their work which drives up unrealistic expectations among the desperate and vulnerable. Dimichele et al. discuss this phenomenon specifically in relation to gene therapy in their article "Gene Therapy Ethics and Haemophilia: an inevitable therapeutic future?"

> **Expectations have placed haemophilia gene transfer researchers under pressure to succeed in a scientific domain in which successes are infrequent and progress is necessarily slow. These same expectations have fueled a perception of gene therapy as the inevitable therapeutic goal for the youngest children with haemophilia. (145)**

When first introduced, gene therapy stirred up much hope, but so far the progress has been slow. A recent article in *USA Today* highlights the disappointing results, pointing out that "after more than 900 clinical trials, gene scientists can claim few real successes and even the technology's longtime supporters say gene therapy has developed far more slowly than they had expected" (Szabo L7). Inflated expectations and dismal results are fueling false hopes among those who truly suffer, which makes it difficult for this controversial therapy to earn the crucial support among the public and within the government.

Fueling false hopes is deplorable, but causing physical harm or death marks a serious abuse in the state of this so-called elixir of life. When discussing scientific medicines, Porter raises the concern that

> **many procedures benefit doctors and other medical professionals and technocrats more than patients, while others are positively harmful. Though new drugs have to surmount the hurdle of randomized double-blind trials before they may come onto the market in western nations, strict trials have rarely been conducted for myriad other medical procedures. (687)**

A rush to market with unproven medical technologies benefits the medical establishment and its researchers by boosting careers and creating celebrity doctors, yet it can seriously harm the patients. Gene therapy has seen its share of this rush-to-market mentality through the highly publicized death of the 18-year-old liver-defect patient Jesse Gelsinger. An article in *Nature* points out that after his death "serious faults were soon found in the way that the trial was conducted. Patients had been inadequately informed of the potential risks, despite evidence of problems" ("The trials of gene therapy" 107). Hasty trials of new medical technology without appropriate evidence supporting the therapy's safety certainly made headlines and created scientific celebrities of the researchers involved prior to the tragedy. However, even more troubling is the "non-immediately life-threatening nature of Jesse [Gelsinger's] genetic disorder and the availability of safe alternative medical treatment for his metabolic illness" (Dimichele et al. 148). Gelsinger lost his life by entrusting his life to medical researchers who very selfishly opted for a riskier and unproven alternative from a variety of other safer treatment alternatives. Such behavior constitutes a serious abuse and as a result, has seriously damaged the field's reputation. It dehumanizes patients and is evidence of what Porter calls "forsaking the patient for science" (683). Such irresponsible haste only tarnishes the reputation of gene therapy, and is counterproductive in earning the support with the public and the government.

There are times, however, when the outcomes of what Porter describes as rushing to market without adequate testing can actually benefit the patients. When a trial to cure a Parkinson's patient was being conducted in 2003, Grady and Kolata reported in *The New York Times* that "leading experts in gene therapy and Parkinson's disease expressed concern [that] the experiment was going forward without evidence in monkeys that it could work, and that it held the possibility of harm" (A1). But a year later the patient appeared to have improved. Time will only tell whether the treatment's success is permanent, but as of now the patient was quoted in the *New*

York Magazine **saying: "My tremors are almost totally gone" (Marx par. 4). High risks often offer high payoffs, while low risks may not offer any payoffs at all. In this case the stakes are high and human life is at risk, but endless waiting for a safely developed cure may also result in a loss of life. A careful balance in this controversial aspect of gene therapy must be achieved in order not to sacrifice progress and avoid the risks.**

The very controversial nature of gene therapy is what could make it into a "knight in shining armour or a new body-snatcher" (Porter 669). The fact that it is receiving so much positive and negative attention suggests that there is an almost equal possibility of its success or failure. Researchers obviously want to keep the public sold despite uneven results from clinical trials. After interviewing several researchers, Harris notes that: "despite the problems [gene therapy] is still routinely heralded as the next big thing, and the field's researchers get a bit defensive when discussing the many problems that have plagued it" (A16). Their defensiveness serves to protect the overarching and all powerful medical establishment. Porter explicitly points to this establishment by describing the twentieth century as the age of an

> **expanding medical establishment, faced with a healthier population, [which] is driven to medicalizing normal events like menopause, converting risks into diseases, and treating trivial complaints with fancy procedures . . . everyone has something wrong with them, everyone and everything can be cured [and] extensive and expansive treatments are . . . urged. (718)**

Expansion of influence and power is a natural desire of any field which aggressively drives towards success. This ensures adequate financial and political support necessary for progress. Yet this over-aggressiveness and expansive tendency has led gene therapy in the wrong direction. Dimichele et al. point out that the reputation of gene therapy researchers has "been tainted by overt financial interest in the outcome of these trials; unclear communication of potential conflict of interest to clinical trial participants; and either failure or delay in reporting many adverse events" (150). The power of the medical establishment is evidenced by the consent of patients to unproven treatments, while at the same time potential conflicts are not being communicated, and adverse events are not being reported. This only demonstrates the lack of vision for potentially disastrous future consequences, and at the same time

jeopardizes the prospects of gene therapy ever becoming a true success which necessitates setting up frameworks to prevent abuses while not hindering the progress of gene therapy research.

Even without adequate data to show that the therapies are safe for the patients, gene therapy, for some, is possibly the only hope. This seems to be the only instance where Porter's idea of the establishment's aggressive drive to extensive and expansive treatments can be justified. In cases of Severe Combined Immunodeficiency (SCID), gene therapy treatments have had the only success. It was reported in the journal *Science* that since the trials began in 1999, gene therapy has been able to restore the immune systems of about 17 children, while three children developed leukemia and one died in 2004 ("Panel Urges Limits on X-SCID Trials" 1544). The risk-benefit ratio is not overtly favorable for gene therapy treatments, and patients suffering from SCID should only be treated when all other options fail. However, as it was pointed out in the journal *Nature* by Cavazzana-Calvo et al., "even with the risk of leukaemia, gene therapy is still a much better therapy than mismatched bone-marrow transplantation for SCID patients" (780). The ethical decisions concerning the treatment in such extreme cases seem to favor the risky and aggressive attitudes of the powerful medical establishment; however, in the rest of the cases a much more careful approach is necessary to avoid abuses and to retain the support of the public and the government.

With its messages encouraging more treatment and medicalizing normal events, the medical establishment may also eventually lead to risky non-therapeutic treatments. Porter sees it as an irony that "the healthier western society becomes, the more medicine it craves" (717). He sees medicine becoming "the prisoner of its own success having conquered many grave diseases and provided relief from suffering but [one that has become] a service industry, on tap to fulfill whatever fantasies its clients may frame for their bodies" (717). Western society being saturated with therapeutic treatments, and with the encouragement of the medical establishment itself, has started to look beyond therapeutic interventions and into non-therapeutic enhancements. H. Lee Sweeney, a gene therapy researcher working on muscle wasting disorders, notes that "gene therapy could transform the lives of the elderly and people with muscular dystrophy [but] unfortunately, it is also a dream come true for an athlete bend on doping" (63). Medicine as "service industry" fulfilling the clients' enhancement fantasies would certainly not be limited to athletes, but the fact

that sports are explicitly mentioned makes this domain the most likely guinea pig. This will certainly tarnish gene therapy's reputation if it becomes a therapy that provides unfair advantages in athletics. If we start engineering super-athletes rather than improving the health of the general population we will certainly miss the therapy's objectives of improving people's lives. Sweeney also wonders whether in the future gene therapy might become "so commonplace for disease, that manipulating genes to enhance performance will become universally accepted" (63). But Longman in his article from *The New York Times* notes that the American society already "tolerates other types of enhancement, from caffeine stimulation of coffee to breast enlargement to erectile function" (A1). This puts gene therapy on the slippery slope from therapeutic interventions to enhancement. If gene therapy becomes safe and effective for therapeutic purposes, and the public already tolerates some types of enhancement, it will only be a matter of time until athletes will begin to enhance their physical capabilities. Allowing gene therapy to become the means of unethical enhancements in high-profile sports will not help to achieve the broad- ranging public and governmental acceptance and support crucial for continued financial support of ongoing research activities.

Porter further asserts that "medical consumerism—like all sorts of consumerism is designed to be unsatisfying" (718). While thinking about the enhancement desires in our society, it is not hard to imagine this unsatisfying consumerism fueling uncontrollable and deadly desires. In light of that Longman describes a shocking statistic: "In a 1995 survey, nearly 200 aspiring American Olympians were asked if they would take a banned substance that would guarantee victory in every competition for five years and would then cause death; more than half answered yes" (A1). This is hopefully an extreme example of the desire for enhancement no matter what the costs, but it is clear that gene therapy has the potential to fuel a deadly enhancement race in sports, which is far off its original goal of eradicating genetic disorders. Furthermore, detecting genetic enhancement will be much harder than detecting conventional doping (Sweeney 68). Gene therapy has the potential of forever changing the nature of sports, leading us to wonder whether we will need separate competitions for enhanced and non-enhanced athletes, further fueling criticism even in light of legitimate successes.

When it finally becomes technically possible, enhancement certainly can and will spread beyond athletics. Porter notes that "modern biomedicine is seriously

challenging and changing our notions of what a human being is, of what it is to be human" (668). The effects of enhancement on human nature still remain to be seen as this subject has been fiercely debated by medical ethicists, but such scenarios always conjure up negative connotations. Certain forms of gene therapy, namely germ-line gene therapy which modifies sperm and egg-producing cells, will give the parents the ability to affect the future generations. Robertson who analyzed this topic extensively in his article "Procreative Liberty in the Era of Genomics" argues that "while much of the resulting control will operate by excluding undesirable genomes [from embryos], attempts to rewrite or engineer section of the genetic code of prospective offspring may also occur" (440). Such notions immediately bring us back to the slippery slope argument. Manipulations of embryos would begin with strictly therapeutic purposes in mind and would attempt to eradicate genetic disorders from the very beginning of a human life. But if the technology allows us to modify or remove a section of the genome causing a deadly disorder, what would stop parents from the temptation of enhancing or adding genes controlling the height or even the intelligence of their offspring? Robertson comments on this issue further by saying that: "Many persons would find genetic manipulation of offspring to engineer traits as the epitome of 'designing' or 'manufacturing' a baby, of turning the 'gift' of a child into a product acceptable only with those designed traits" (475). Once children are a product being designed and manufactured, we begin to appreciate the concerns voiced by Porter about changing notions of what a human being is. It is hard even to combine the words "human," "design," and "manufacture" in the same sentence without immediate negative connotations, while the criteria of "acceptability" recalls eugenics and similar discriminatory practices. A child will no longer be considered a gift, but rather a designed or manufactured product, which clearly challenges the notion of what it is to be human.

Such trends are seen as a grave danger by other ethical theorists as well. R.E. Ashcroft in his article "American biofutures: ideology and utopia in the Fukuyama/Stock debate" summarizes Francis Fukuyama's concern that "if we change the genetic and psychological constitution of humans significantly, we risk destroying the idea of human unity, undermining the ideal of personal autonomy, and erasing the basis of moral equality" (Ashcroft 60). Similar concerns are addressed specifically in regards to gene therapy by Richter and Bacchetta in their article "Intervention in the Human Genome: Some Moral and Ethical Considerations." They

point out that "germ-line manipulation is a violation of a putative human right to a genetic patrimony that has not been artificially manipulated" (313). Fukuyama's ideal of personal autonomy would be grossly violated if we attempt to change a person's traits and characteristics before she is even born to voice any opposition. Every human being has a right to an unmodified set of genes inherited from its parents, and by allowing gene therapy to proliferate into domains for which it is not intended, we are risking gross violations of human rights as a result of whims of the parents. Such serious threats to the notion of what it is to be human and have personal autonomy will certainly not help gene therapy win the public and governmental support that it needs to achieve its legitimate and ethical goals.

While germ-line manipulation is controversial even in the therapeutic sense, non-therapeutic enhancement is often the most commonly mentioned and most controversial aspect of gene therapy. Porter describes it in a broader sense by saying that "affluence, education, leisure and many of the values promoted by corporate capitalism have stoked a culture of individual enhancement and free and active choice, [and] it has become the done thing to shop around for healing" (Porter 689). The affluence of the western society has made it possible to "shop around" for personal enhancement, but Porter fails to mention that not all segments of the society will have truly equal access to such "shopping around." Walters and Palmer in their *Ethics of Human Gene Therapy* argue that "health-related physical enhancements and intellectual and moral enhancements for persons who already are functioning within the normal range seem . . . more problematic [especially in regards to] the allocation of these enhancements" (131-132). Gene therapy will almost certainly be very expensive, at least in the foreseeable future. Not all segments of the society will have equal access to this shopping around for healing or enhancement, which will certainly lead to inequalities and widen the gap among social classes. This will further tarnish gene therapy's image as discriminative, tailored to serve the elites, and will not help to win the broad support from the public and the government.

There is a clear need for some kind of guidance to draw the line between therapeutic and enhancement forms of gene therapy. Walters and Palmer note that "only this kind of line drawing will focus the attention of gene therapy researchers on genuine medical problems, that is, human disease and human health" (92). This is a key point, since by creating such a boundary, the government could control which gene therapy research efforts are supported financially. Substantial funding

resources originating from the government will attract the best and the brightest researchers to subfields of gene therapy which the government can deem as therapeutic. However, drawing such a line between treatment and enhancement might not always be straightforward, as noted by Juengst and Walters in their article "Ethical Issues in Human Gene Transfer Research."

> **To the extent that disease prevention is a proper goal of medicine, and the use of gene-transfer techniques to strengthen or enhance human health maintenance capacities will help achieve that goal, then the treatment-enhancement distinction cannot confine or define the limits of the proper medical use of gene transfer techniques. (704)**

In certain instances in order to treat a disease it would be necessary to enhance certain traits, thus the difficulty in deciding what is considered to be therapy and not enhancement. An example of this dilemma would be the enhancement of immune-system function. Walters and Palmer note that such enhancement would be morally justifiable if it "assisted in preventing disease and did not cause offsetting harms to the people treated by the technique" (110). Even Porter would most likely approve of this distinction, and would not question it in terms of violation to the notion of what it is to be human. Such specific forms of enhancement, with a clear ultimate purpose of combating a disease could safely be considered therapeutic. It is also very likely that this form of enhancement would get the full support from the public and the government.

The government has ways of influencing or guiding gene therapy in the right direction, but gene therapy should not to be directly regulated, as that will only force the best researchers to relocate to countries with friendlier policies. The government needs to provide a set of incentives so that gene therapy can thrive, and strengthen those areas which hold the best promise for the greater good. Ashcroft notes that both Fukuyama and Stock, ethical theorists on the opposite ends of the conservative-liberal spectrum, "overlook the positive contribution that government could make to equalizing the balance of social power. . . and encouraging research and investment into improving collective welfare and the welfare of the weakest and most vulnerable" (60). The government cannot and should not strictly regulate gene therapy, but it can provide selective funding to the therapeutic subfields and let them flourish by attracting the best researchers. Any aspiring scientist in the field of gene therapy would be drawn to those subfields, as government money still substantially

controls most of major research. Another negative point about regulation is that too much regulation scares away investors, which heavily supplement the funding available from the government. Cavazzana-Calvo et al. note that "in the absence of industrial investment it is unlikely that gene therapy will eventually deliver on its promises" (779). Thus not only will certain forms of gene therapy not deliver to their full potential, they may not deliver at all if investment-friendly policies are not established. Gene therapy not delivering on its promises because of lack of funding would certainly not serve the public interest. Furthermore, Ashcroft notes that the "[government] at its best can act as a brake and the medium of social control over the most vicious instincts of would be exploiters of others" (60). Thus the approach of control through funding is not fool-proof, and some unethical forms of gene therapy are still likely to emerge. However, the possibility of strict government regulation impeding progress is far worse. Regulation would only lead to a blind belief that unethical forms of gene therapy are prevented, while in essence nothing would be stopping them from proceeding at offshore laboratories. The government, with the support from the public and the industry, must provide incentives for scientists to stay in this country and push gene therapy closer to success.

Gene therapy promises to become a major medical force in the 21st century, but like any panacea, may prove only to be a hypothetical remedy mixed up by some white coat alchemist seeking fame and profit. Although gene therapy is currently hampered by countless setbacks and has not delivered on many of its promises, it seems as if time and patience are key factors when it comes to such complex biotechnologies. The theoretical foundations underpinning its success are in place, but science is always more difficult in practice. In order for gene therapy to deliver on its promise, it must avoid the pitfalls and abuses typical of modern scientific medicine. Its most controversial aspects such as non-therapeutic enhancement and resulting deaths from untested methodologies must be avoided in order to gain the full acceptance from the government and the public so that the crucial funding will allow researchers to realize gene therapy's full potential.

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COMMENTARY: Douglas Piccinnini

Did I request thee, Maker, from my clay
To mould me man? Did I solicit thee
From darkness to promote me?
John Milton, *Paradise Lost*

It is summertime. The sun beats down outside and you watch television in a perfectly air conditioned room of sixty-eight degrees Fahrenheit. Your cell phone rings and it is a friend. She asks you to take a drive to the beach. To lay out on the sand and go swimming in the sea. It is near noon and the temperature is approaching the mid-nineties. You decide to meet your friend and pack a light picnic to share on the beach as you tan your bodies and perhaps steal a few minutes to read from a new paperback novel set in Europe which discusses the historical bluffing of our ancestry. The heat is intense and you decide to open the cooler and refresh with a bottle of spring water and some grapes. Red seedless grapes. Specifically the Red Flame, a varietal that is fairly new to the food market and continues to grow in popularity. It is a cross between a seeded grape and a round seedless grape. It is here under the sun, sipping chilled water which has traveled hundreds of miles to meet your lips, that you first encounter biotechnology. The seedless grape.

Gene therapy is perhaps a more recent and intriguing intrusion of biotechnology into everyday life. This new biotechnology involves the correction of defective genes responsible for disease development in human beings and, unlike the seedless grape, carries the potential to change human life as we know it. In Sebastian Lesniak's "Gene Therapy: Promise, Problems, and Abuses" this new biomedicine is ostensibly brimming with promise in allowing what would be an elegant shift in modern medicine from medication to reformation and prevention. As Lesniak notes, "gene therapy has the potential to eliminate the root causes of certain diseases by repairing or modifying a patient's genetic code." Essentially what is going in gene therapy is a reconstruction of the human genome—the blueprints, or genetic codes, that biologically make people who they are.

But if you change the blueprint, the structure is invariably altered as well. In other words, removing or enhancing one facet of a person's genetic code may prove to have significant effects on that person. It is not as simple as erasing lines and figures on a blueprint for a house and replacing, for example, bay windows with a balcony or adding a spiral staircase to liven up the spatial arrangements of the vestibule. The

possible implications of gene therapy seem to be far more complex than simple addition or subtraction, and Lesniak is aware of this fact, frequently suggesting that research in this field must be "carefully guided through government and public supported policies and incentives" in order to "flourish." Yet at the same time, the potential benefits, as Roy Porter suggests in *The Greatest Benefit to Mankind*, allow gene therapy to be viewed as either a "knight in shining armour or a new body-snatcher." In this sense, what Porter suggests by the latter involves not only adding bay windows and a spiral staircase, but building a new house altogether.

It very well may be a battle for the semanticist to decide whether eliminating Jane Doe as a carrier of male pattern baldness can qualify as symptom of a "body-snatcher," but eliminating her risk for breast cancer after thirty-five might significantly alter the chain of events in her life. Will Jane live longer? Might she not have developed breast cancer anyway despite a long genetic history of cancer in her family? Perhaps the rudimentary notions of chance are paired up against larger ethical and social issues. If Jane Doe's embryo is altered *in utero*, is Jane still Jane? Can Jane ever still be Jane once science interrupts her biology?

Lesniak provides the example of a Parkinson's disease patient who, after genetic correction through gene therapy, reported that his "tremors [were] almost totally gone." While this example of treatment occurs at a later life stage—seemingly at a time when the patient has a developed sense of self—what is to say that this disease has somehow reinforced or established some kind of personal characteristics which are attributed to his struggle with this disease? The kind of logic that might suggest: whatever doesn't kill me makes me stronger. But does struggle somehow build character? And as insane as it would seem, do not our own misfortunes and the misfortunes of others contribute to a sense of hope and love, perhaps an appreciation for the fragility and wonderment of human life? Would gene therapy then allow for a medically uneventful life, aside from the occasional accident or broken bone? Here we travel into uncertain waters, swirling with a myriad complications and implications. For starters, who or what "case" is deemed worthy of treatment?

Lesniak cites Porter on the twentieth century as an "expanding medical establishment faced with a healthier population which is driven to medicalizing normal events." And yet the potential of the wealthy to have access to top medicine is already seen in the growing number of elective surgeries among those in the upper crust with disposable income. Will gene therapy be accessible to the lower spheres

of society? Or will it serve as a further means of segregating those who can afford to be well from those who cannot? Even so, this type of slippery slope which Lesniak addresses seems to be far off in the future as gene therapy is still in its infancy.

Ultimately, it would appear that gene therapy is just another feature of modern life, another matter of quantity not quality. Yet gene therapy in its best efforts might be able to achieve both: longer healthier lives without the stressors of sickness. However, while scientists, doctors and medical professionals seek ready made cure-alls for the minor infractions of everyday life, it seems that somewhere along the line people have forgotten how to live. Have they?

As Lesniak cites, "medical consumerism—like all sorts of consumerism is designed to be unsatisfying" and, with the seemingly endless roof on innovation in all forms of technology, it is perhaps frightening to think of what can be done next. Will the seedless grape become the pre-chewed grape? To the extreme, such a suggestion seems ridiculous but, left unchecked, biotechnology might dramatically alter the way in which a human being is a being. Humans, like the grape, could potentially be manufactured and bred to perfection, a kind of accelerated social Darwinism that calls to mind the work of certain nationalistic tyrants.

By eliminating sickness and genetic disorders and extending life expectancy, does gene therapy promote life or does it question its very nature? For will birth take place in the tormented laboratory of some Dr. Frankenstein, who after creation deems his own god-like handy-work to have produced a genetically-calicoed monster? Or was Dr. Frankenstein's response merely an overreaction to the perks of better living through technology? While an endless set of hypotheticals can be produced at this developmental stage in gene therapy, one must ultimately decide, as Porter suggests, not only what our notions of a human being are but, more importantly, "what it is to be human."