

Genetic Modification and Egalitarianism: Distinguish and Distribute

By Emilia Lopez

Winter 2004, University of California at Santa Cruz

Researched and written with the support of a CBSE Diversity Award in Genomic Science

"The magnitude of an 'advance' can be measured by the mass of things that had to be sacrificed to make it; mankind in the mass sacrificed to the prosperity of a single stronger species of man—that would be an advance."

--Nietzsche, The Genealogy of Morals (2:2)

Recent studies with gene therapy or genetic modification have demonstrated their ability to create a society of genetically perfect human beings. Because it is early in the development of gene therapy many ethical questions have begun regarding *how* gene therapy will be used and *how* gene therapy will be distributed amongst society. Nietzsche's quote suggests that in order for a society to advance as a whole, the weaker inhabitants of this society must fall casualty to this revolution. Quite the contrary, I believe that a genetic revolution ought to be carried out in an egalitarian manner for the reason that genes are inherent to every human being on this Earth and therefore gene therapy ought to be distributed likewise. Our duty is to find a way to *distinguish* between types of gene therapy that will benefit society (i.e., how gene therapy will be used) and a way to *distribute* gene therapy equally. I will illustrate how Nietzsche's notion of "the mass sacrificed to the prosperity of a single *stronger* species" will only lead to the further degradation of society and our struggle to attain social equality.

The employment of gene therapy threatens to further distribute wealth and opportunity unequally, in turn, ostracizing the poor. It is suspect that this treatment will not come without a price and because it is still early in its development insurance companies are unlikely to cover treatments. However, the first steps have already been made to alter a human's genetic make-up, for example on August 18, 2003 a 55-year-old male received gene therapy for Parkinson's disease. It is our duty to decide what aspects of gene therapy will be beneficial to our society and which will not. In order to illustrate my point I will distinguish between two types of genetic modification: preventative and enhancement. My notion of preventative gene therapy is taking anticipatory measures to avoid future maladies (e.g., Parkinson's disease). Enhancement gene therapy is the notion of designer babies, where parents are given a catalogue and pick the traits of their child. I will demonstrate how enhancement gene therapy is superfluous and a mar to the betterment of our society. Above all, I will suggest that we must never lose sight of the fact that it is our duty to find a way that will allow for an egalitarian distribution of gene therapy, in order to stray away from the Nietzschean notion of an *advance*.

I. Update on the Genetic Revolution

On August 18, 2003 the first gene therapy treatment for Parkinson's disease was given to a 55-year-old male at the New York Presbyterian Hospital by Dr. Michael G. Kaplitt. During this 5-hour procedure the

patient was fed a gene therapy agent known as Adeno through a very fine catheter. The aim of this procedure is to inject the patient with *healthy genes* (those lacking Parkinson's disease), by doing this, the healthy genes replace all the defective genes, in turn, reconfiguring the genetic make-up of the patient. Whereby, the patient will never experience symptoms of the disease. Dr. Kaplitt comments:

The goal of our gene therapy approach is to 're-set' a specific group of cells that have become overactive in an affected part of the brain, causing the impaired movements of Parkinson's disease. We hope that this trial, which is the first of its kind, will prove to be a safe treatment to allow gene therapy to move forward for Parkinson's disease and other brain disorders.¹

According to Dr. Kaplitt this procedure will pave the way for different types of therapy related to the brain. It is important to notice that the type of gene therapy described by Dr. Kaplitt is being used to prevent one from experiencing illness. Since the early 90's gene therapy has been used as a preventative science to treat conditions such as cystic fibrosis, cardiovascular disease, AIDS, and cancer ("Cornell Chronicle," Timothy S. Paul). This technology will benefit those individuals faced with the onset of life-threatening conditions by simply replacing the bad gene with a

¹http://www.news.cornell.edu/Chronicle/03/8.28.03/W_eill_Parkinsons.html

good one. Preventative gene therapy will allow people to refrain from experiencing onset symptoms and diseases. Therefore, prospective onset patients will never undergo a *curing* process rather a *preventative*. Biologist Daniel Koshland Jr. of University of California at Berkley states:

We should start, perhaps, with the question raised by some who say we shouldn't tamper with the germ line. I frankly don't understand these people. Where are they living? We are already altering the gene line right and left. When we give insulin to a diabetic who then goes on to have children, we are increasing the number of defective genes in the population. No one is seriously suggesting we refuse to give life-saving drugs to genetically disadvantaged people.²

Koshland raises the questions: *How* should gene therapy be used? And what does it mean to be genetically disadvantaged? I believe it is our duty to *distinguish* between types of therapy that will be beneficial to society and types that will not. But in order to do this we must take an accurate account of what our society values, in so far as, what diseases are worth repressing? The website Genetics and Society offers another way to utilize gene therapy. Its supporters suggest the notion of designer babies and enhanced elites: genetically and aesthetically perfect individuals.

Advocates of this new techno-eugenics look forward to the day when parents quite literally assemble their children from genes listed in a catalogue. They celebrate a future in which our common humanity is lost as genetically enhanced elites increasingly acquire the attributes of separate species.³

This touches on the notion that gene therapy can be used to *enhance* our aesthetics and possibly physical capabilities. Are there affinities between enhancement therapy and preventative therapy? It seems to be the case that preventative therapy has less room for error, meaning, we as a society will benefit more from preventative therapy because we are replacing bad genes (that cause illness) as opposed to assigning new superficial gene that promote looks. It is our duty, we must find a way to *distinguish* and clearly define types of therapy and find a way to *distribute* it equally among our society.

II. Two Types of Gene Therapy

Preventative gene therapy is the idea of taking preemptive measures to eliminate onset of genetic maladies that could prove to be life threatening. Examples of these maladies are diseases and conditions such as Parkinson's, cystic fibrosis, AIDS, and cancer, diseases that patients pay hundreds and

thousands of dollars in attempts to cure. Treatments for these types of ailments are extremely pricey and still only treatments not *cures*. Patients are forced to surrender to a not-so-benevolent and loving "Pharmaceutical God" in order to save their diseased bodies. If it is within our power to prevent these life-threatening conditions, is it not the case that one *really* expensive preventative treatment is far better than multiple *really* expensive treatments after your body has already begun to show signs of disease? If gene therapy can offer people healthier and longer lives without being plagued by their genetic maladies then why not utilize gene therapy as a method of prevention? I believe this is the type of revolution that will benefit society as a whole. The uses for gene therapy are endless, but, unfortunately, the notion of designer babies and enhanced elites seems to follow.

Designer babies and enhanced elites is enhancement gene therapy. Enhancement gene therapy attempts to make an already functional person better than they are aesthetically. Enhancement gene therapy could be used to make someone taller, to promote hair-growth, or to give them browner eyes. Two questions lurk behind the notion of designer babies and enhanced elites: 1) Why should we make a functional person better and 2) What characteristic are undesirable and ought to be repressed? To address the first issue enhancement gene therapy is like an extreme form of plastic surgery, insofar, as it aims to make aesthetics more pleasing. As a result of enhancement gene therapy many socio-political problems could result. For instance, those financially inept citizens that cannot afford to be enhanced could be further ostracized. The Nietzschean notion of an *advance* comes into play and we must question how many will be sacrificed for the sake of aesthetics? Regarding the second issue, we must ask which characteristics will we choose to repress? It seems as though it would be quite detrimental to our society if we allow certain traits to be repressed, while we allow others to thrive.

III. Ostracism and Racism: The Nietzschean Advance

First of all, it seems obvious that gene therapy will not come cheap and furthermore will not be available to everyone. Because gene therapy is in its beginning stages, insurance companies are highly unlikely to cover a procedure with results still in the developmental process. However, in order to learn from gene therapy we must test it by experimenting with preventative gene therapy procedures. The problem we run into with gene therapy is that it is a process that completely changes the patient's DNA. Such a drastic procedure will no doubt cost time and money. Parkinson's disease develops around the age of sixty, therefore if a person is treated when he is 55 years-old the results will take a minimum of 5 years to observe. Although the wait may be beneficial in the long run, it is evident there will be a time period in which only an elite group of people will get the help they need. I believe this for the reason that gene therapy is new and it will take a while to be put on the market and until it reaches the market there is less of

² Online Interview, March 22, 2004, Professor Daniel Koshland Jr. of University of California at Berkeley

³ <http://www.genetics-and-society.org/overview/threshold.html>

a chance to distribute these treatments equally. Gene therapy is like all other forms of medication or preventative procedures, in that the development of these procedures will take both time and money to be perfected, as well as time to become more widely available to the public. Due to the fact that gene therapy can be a preventative procedure its future looks good, in that it saves patients from costly insurance battles and an inflated pharmaceutical market. While only a select few will benefit in the beginning it is necessary to develop the science early so that it can be more widely available in the future. The idea of enhancement gene therapy seems to follow from preventative gene therapy. I believe we ought to perfect the science of preventative gene therapy first, but it is my worry that enhancement gene therapy will follow and I believe enhancement gene therapy houses many problems.

While gene therapy in general seems to immediately threaten the egalitarian distribution of good genes, the unequal distribution of enhancement gene therapy could be more permanent. The idea of making designer babies seems like it would be even more difficult to distribute equally among society for the reason that it is luxury rather than life-saving. Let us examine the case of plastic surgery in comparison with enhancement gene therapy. Most plastic surgery is used to enhance physical appearance (i.e., breast implants, liposuction, etc.) These are all costly procedures that are mostly paid out-of-pocket. A major insurance company, Blue Cross, will not cover plastic surgery enhancements and is hesitant to cover reconstructive plastic surgery as well (Interview, Shawna Valbuena, Blue Cross Insurance Representative). I feel it would be safe to assume that insurance companies would treat enhancement gene therapy the same as plastic surgery because it parallels as a luxury. Characteristics such as enhancing height and hair-growth are superfluous when Parkinson's patients are trying to postpone death. It is not the case that if a person is not at least 5 foot 5 inches, they are not happy. I know many people who do not meet that height standard and are completely happy. It would be nice when trying to reach for dishes that are high atop a shelf, but it is not a life threatening situation.

If we were to allow enhancement gene therapy for the purpose of aesthetics, what physical attributes would make the catalogue and which will be excluded? I believe there is value in the quirks and absurdities of appearance. It seems ethically wrong to decide which physical attributes are desirable and which aren't. Take for instance Down syndrome; this is a condition that many would say is undesirable. However, my little sister (19 years old) has Down syndrome and she has expressed value in her struggle with her disease. If we were to move past this notion of "what characteristics make the list" it seems possible that a sub-group (I will refer to this sub-group as Group B) may rise and would chose not to partake in the genetic revolution. While Group B may be exercising

their freedom of choice we cannot safely assume that their decision will not be ridiculed by Group A and possibly lead to the degradation of society and our struggle to attain social equality. Take for example the movie "GATTACA." The main character was not allowed to be an astronaut because he was not genetically perfect. In order for him to succeed in society (Post-Genetic Revolution) and become an astronaut he had to fake his genetic perfection.

IV. Drawing Lines

The problem with distinguishing between preventative and enhancement gene therapy is that the line is fuzzy. With the constant destruction of the ozone-layer it could, one day, be the case that we all want darker skin to protect us from ultra-violet light. If for some reason we suppress that gene and later need it, we'd have to go back and re-work the gene line. Meanwhile, all those with light skin would be at a severe disadvantage. Conversely, if we do not allow enhancement gene therapy, darker skin, maybe considered an aesthetic enhancement and because we find luxury a problem we may not allowed gene therapy for darker skin, although in this case it would be useful. Distinguishing between enhancement and preventative therapies is tricky, however, I feel that it is necessary to draw these lines in order to refrain from the Nietzschean notion of an *advance*.

V. Conclusion

Gene therapy has already been employed in our society. This is a process that is irreversible and because of its permanence must be considered carefully. What is most important of all is to *not* lose sight of the fact that it is our duty to utilize the science in a way that will benefit society as a whole.

I feel that immediate preventative gene therapy treatments will be unequally distributed but that they are necessary in order to properly develop the science. Gene therapy will only become beneficial to our society if we understand it thoroughly. On the other hand, I feel that enhancement gene therapy is but another form of plastic surgery that is not at all necessary, but a luxury. I feel that enhancement gene therapy loses sight of the fact that this science ought to be used to benefit society and save lives as a whole, instead of cater to a select elite. My worries that enhancement gene therapy will only further ostracize the poor and possibly give rise to new forms of racism are socio-political worries that could be realized if we allow genetic modification to get out of hand. I feel that it is more important for our government to support life-saving rather than luxury treatments, and because of this we must refrain from enhancement gene therapy.

In a world already plagued by the unequal distribution of wealth and opportunity it would be absurd to spend tax dollars on a science that will only further segregate society. It is our duty to be tactful when utilizing these treatments and furthermore analyze all possible consequences of gene therapy.