04D008I

TAS
Project Number: 20939 IQP TAS-7592 - 43

The Bioethics of Prenatal Screening

An Interactive Qualifying Project
submitted to the Faculty of
WORCESTER POLYTECHNIC INSTITUTE
in partial fulfillment of the requirements for the
Degree of Bachelor of Science
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Date: March 1, 2004

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IQP Abstract

In our project we explore both sides of the prenatal screening debate. We do this by looking at issues such as religion, abortion, and potential medical advances. We also discuss the risks involved with the different methods of screening, as well as the disabilities that are screened for. Our goal is not to come to a conclusion of right or wrong, but provide all possible information as to allow someone to make an educated decision for themselves.

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Introduction

Bioethics is a very important component of science and technology as the world changes. As technological advancements are made, the ethics of what is good and bad according to the public eye tends to be skewed. Bioethics is the study of ethical and moral implications of new biological discoveries and biomedical advances, such as in the fields of genetic engineering and drug research. This project will be a study of the ethical implications of prenatal diagnosis. This is because there are many controversies that surround the ethics of prenatal screening, its purpose, as well as the repercussion of what the prenatal diagnosis may show.

Prenatal screening is a technique that has evolved greatly since it was first realistically introduced to the public in 1949. Prenatal screening is particularly relevant in bioethics; this is due to the fact that there are completely opposing views that are based on people's moral values when discussion of said prenatal screening is brought about. The purpose of prenatal screening initially was to prevent birth defects, along with providing therapeutic techniques once possible defects were realized; however, after many years of prenatal screening, some people believe that it has been being used to find birth defects that in many cases are impossible to cure in drastic cases. In such cases, the only "cure" is aborting the fetus, thus bringing to light the moral discrepancies of prenatal screening. Is it worth aborting your baby because they find out that the baby is going to have a certain disease? Is abortion justified due to particular diseases? This is what our group wants to discuss and make a point about. We have decided that this is important to discuss because there are many conflicting opinions that modern society has regarding the moral issues of abortion as well as prenatal screening in general. We are splitting into opposing sides within our group. After arguing our cases from both sides, we will form a conclusion regarding our groups feeling towards prenatal screening. This could be the same as when we started or our opinions could change regarding the evidence we have found.

What we want to find out is whether prenatal screening is a good or a bad thing. Some people feel that performing this type of technique does no good for the baby or the parents. There have been many cases in which the parents decided to have an abortion after they found out that their baby was at risk. Obviously, in such a case, there seems to be no good regarding the performance of prenatal screening. However, some also argue that if the parents are willing to have an abortion after finding out that the baby will have a disease, they are not fit to have a family anyway. The people who feel that prenatal screening is a good thing prove their case because many times when a baby is said to have a disease prior to being born, it allows the parents to research and find out more about the disease and how to treat it upon the birth of the baby. In these cases, the prenatal screening is beneficial to both the baby and the parents. In such incidences, the baby is very much able to live a full and happy life and the parent will be less surprised and can plan accordingly.

With the advances in prenatal screening and diagnosis, abortion is not the only problem created. Recent advances will give scientists the ability to pinpoint individual genomes responsible for particular traits. This technology could be great as far as curing diseases and reversing mutations, but it is scary to think that scientists will be able to manipulate the human genome. Who is to say that this technology will only be used for good and will not advance into a time of creating "designer babies?" Our group will also be looking at the possible negative aspects of the development of an entirely new science of genetic manipulation as an offspring of genetic screening.

The ethics of the idea of being able to genetically screen an unborn baby for diseases and disorders before it is born is one that has been debated for about half a century. People argue about the rights of the parents, the rights of the baby. The argument always seems to flow down similar paths, usually changing into a debate about playing God, or it moves up to an argument about the ethics of abortion. This paper will not follow those paths, although it must be acknowledged that abortion may be a possible decision made by parents who receive an unfavorable test result. Focus must be placed on the decision of whether or not the prenatal genetic screening is ethical.

There are also a few different levels internal to this debate. Assume for a minute that everyone in the world agrees with abortion, or is pro-choice. A pregnant couple who is fully ready (financially, mentally, maturity level, quality of life is ideal for raising a child) and has full intentions of having the baby gets the unborn baby screened. If the results come back that the baby will have a fatal disease and die by the age of 10, the couple will get an abortion and try again. In essence, the test led to the baby being denied of 10 years of life. This is the most controversial and debated level of the argument. On the next level down, say the test returned a result that the baby would be retarded, or have something like Down's syndrome, and the couple gets an abortion and tries again. Now the baby was denied of its whole life because of the test. Many more people would against prenatal screening in this argument.

The most extreme cases would be if the couple wanted a blonde baby, or some other neutral quality that may lead to the parents deciding to try again. This may seem ridiculous at first, but in actuality, it is a real world scenario that, though many may find it very sadistic to deny someone of life because of the way they are going to look or how smart they are going to be (especially those completely against abortion anyways), is completely legal.

Still, there are disorders that are life threatening such as Tay-Sachs disease, which is a fatal genetic disease that a debate rages on about. A person who is born with this disease is going to die; to this point, there are no cures for Tay-Sachs. For the majority of children born with Tay-Sachs they will only live to be about 5 years old, and for people who have late onset Tay-Sachs, they will only live to be about 20. If the parents were to find out about this disorder before the child is born, they have the choice to terminate the pregnancy then or to allow the child to be born, knowing that it is going to die before they do. Then the same ethical debate about whether or not the parents should be allowed to know this kind of information goes on.

To others, if there are techniques available to the parents to obtain this information then there is no reason that the parents should not be allowed to know; they may not care whether the parents terminate the pregnancy or not, they are only defending the right of the parents to obtain said information. And, to some, knowing genetic information about a child, such as whether or not the child has Down syndrome, is the difference between termination or carrying the fetus to term; they may not want to deal with having a child with special needs and don't want to put themselves and the child through that kind of a life.

In the world today, many controversial subjects may never be answered. Prenatal Screening is one of those subjects. Over the past few decades, prenatal screening has become more popular than ever. With the advancement of technologies, these screenings are becoming more accurate. Families that are expecting a newborn are being screened to make sure everything is going well with the birth, and that there is nothing wrong with their son or daughter. However, having this process performed could result in some painful decisions. It is not actually the idea of prenatal genetic screening that some people find unethical, but the actions that can occur because of a test result. For example, parents that find out that their offspring will have Down's syndrome may choose not to have it.

Social Concerns Raised By New Biotechnologies

When dealing with a new form of biotechnology there are several broad social concerns are usually raised. Pre-natal genetic disease screening is no different. The President's council on Bioethics writes that, "Biotechnology is bigger than its processes and products; it is a form of human empowerment." [1] This is because the techniques, instruments, and products produced allow human beings to take more control of their lives. This means that to think about the ethics of a new process, instrument, or product one must look past the physical thing itself, look to the way that it is going to affect society.

The first thing to consider is that "a given biotechnology once developed to serve one purpose is frequently available to serve multiple purposes." [2] This means that the people who develop a certain technology may not intend for the technology to be used in

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[1] The President's Council on Bioethics. Beyond Therapy: Biotechnology and the Pursuit of Happiness. October 2003 (Washington, D.C.). Chapter 1, Page 1.

[2] The President's Council On Bioethics, Chapter 1, Page 2.

the manner that it will be used in by society in the future. This consideration is extremely important in the issue of pre-natal genetic disease screening. Many people feel that the technology of screening fetuses for gene mutations can lead to screening fetuses for genetic characteristics that will not cause disease or death. "Determining the gender of an unborn child is not unusual and is done through several methods. The most common are amniocentesis and ultrasound." [3] This is an important impact to take into consideration. People choosing to abort a pregnancy based upon the sex of their child is a very hot ethical debate, and a perfect example of using a technique for means the technique was not originally designed for. "The majority of couples requesting these services are of Asian or Indian ancestry, and they're all looking specifically for a male child."[4] In these cultures, being a woman is considered a burden, someone that has to be taken care of, married out of the family, and a wedding dowry must be offered up. Being a man means a large amount of financial and cultural freedom for that person. These parents can find out through their own communities where to find clinics that are willing to perform these tests. Providing these services can be very lucrative for the clinics because generally the couples will pay in cash and up front. The clinics do not perform the abortion for the parents; however, they will refer the parents to a doctor who will perform abortions specifically for the reason of sex. These kinds of doctors are extremely hard to come by because generally the abortion is done during the second trimester. "A large survey appeared in a journal, The American Journal of Obstetrics and Gynecology in 1992, and it showed that among different groups – obstetricians, genetic counselors, ethicists – all considered sex selection to be unethical, and the authors of that

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[3] Weekend Edition, Sex Selection of Fetuses May Raise Ethical Questions, National Public Radio, HighBeam Research. <http://www.highbeam.com/library/doc3.asp?docid=1p1:28263174>

[4] Weekend Edition.

study expressed concern that selecting the gender of a child is quite different from detecting a genetic abnormality or a defect where termination of the pregnancy may be in the best interest of the child or that family."[5] Many counselors do defend the parent's rights to learn this information and to choose the destiny of their family and their child. Dr. John Stevens, a sex selection clinic director or clinics in California, New York, and Washington, says, *"The doctor's medical, legal, and ethical responsibility is to the patient, to grant the patient full autonomy in their choice of reproductive outcome. You cannot deny the patient the right to information about the sex of the fetus and about the issue to their right to terminate the pregnancy. We must respect patient autonomy. We must be advocates for patients making their own reproductive decisions."*[6] However, in counties like China, there are three males for every two females because of sex selection. Men are having trouble finding wives, and the country is considering outlawing the practice of sex selection.[7] This is an excellent example of what can happen with a technology when it is applied for a use other than its original purpose. However, the important thing to look at here is that when the technology is abused, we as a people make laws against this abuse so that we do not harm ourselves as a society.

The second thing to consider about new technologies and biotechnology as a field in general is what features or characteristics of the human condition we want to improve. This is where the previous negative argument against pre-natal genetic disease screening can be shown as weak. To this point in history, the mainstream of medicine has tried to improve the lives of humans with the development of vaccines for diseases, antibiotics, surgical techniques and equipment, and medicine to ease the discomfort of an un-curable

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[5] Weekend Edition.
[6] Weekend Edition.
[7] Weekend Edition.

condition or disease. Now we can screen for genetic disorders in fetuses, clone whole embryos like Dolly the sheep, and use genetic therapies to treat diseases. The President's Council on Bioethics writes that because of the advent of this new technology and the potential it contains, considering the ethics of the technology means, *"once we go beyond the treatment of disease and the pursuit of health, there seem to be no ready-made standards of better and worse available to guide our choices."* [8] and therefore we must go beyond the normal ethics of medicine. This is very true. However, to suggest that the medical community is going to stray so far from its past beliefs to create a society like the one in Aldous Huxley's Brave New World or to create a race of super-humans is kind of a stretch. [9] However, the move seems to be in the right direction.

The President's Council on Bioethics also raises a third consideration, which is at what price does the technology affect the society as a whole. It raises such considerations as, *"long life might come at the price of less energy . . . superior performance for some might diminish self esteem for others . . . efforts to moderate human aggression might wind up sapping ambition . . . interventions aimed at quieting discontent might flatten aspiration."* [10] As far as a pro pre-natal genetic disease screening is concerned, this consideration might not be very relevant because the only way pre-natal genetic disease screening can affect society at the present time is whether the parents decide to abort the pregnancy. The negative argument to this would be that if the parents decide to abort the pregnancy, they are killing a human being. Many people have personal feelings on abortion, which, however, should not have a bearing on their feelings about prenatal genetic screening. Prenatal genetic screening is not abortion. Prenatal genetic screening

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[8] The President's Council On Bioethics, Chapter 1, Page 2.
[9] The President's Council On Bioethics, Chapter 1, Page 2.
[10] The President's Council On Bioethics, Chapter 1, Page 2.

is a medical technique that is used to screen for known mutations in the genome of a fetus. However, there is a linkage in people's minds that pre-natal genetic screening automatically means abortion if the results are not what the parents want. One of the most widely used techniques is amniocentesis. Amniocentesis involves an ultrasound and the withdrawal of amniotic fluid.[11] The ultrasound is used to see where the needle is being inserted into the uterus through the abdomen. Fluid is then taken from the sac surrounding the fetus, and usually 1cc of fluid is taken per week of gestation.[12]

> *"Amniocentesis can be used to diagnose a large number of genetic and chromosomal abnormalities in the fetus. In addition, it is helpful in the diagnosis of the severity of Rh incompatibility, lung maturity, and neural tube defects (such as spina bifida). DNA testing is available for many diseases. New diseases are being added to this list as genetic research advances."*[13]

Nowhere in any of the descriptions of the techniques of amniocentesis is abortion described. The risks involved with this procedure include *"slight infection or injury to the fetus"*[14] and a smaller chance of miscarriage, however, *"this test is typically performed when a problem is suspected, so the benefits outweigh the risks."*[15] To argue that this technique is always going to lead to abortion is weak. As stated before, the test is generally performed when the pregnancy or the fetus is considered to be at risk. Even if the test were to come up with a negative result, it is the choice of the parents to abort the

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[11] Neonatology on the Web. "Teaching Files: Amniocentesis," 5 September 1995. <http://www.neonatology.org/syllabus/amniocentesis.html>

[12] MEDLINEplus, Online ed., s.v. "amniocentesis. <http://www.nlm.nih.gov/medlineplus/ency/article/003921.htm>

[13] MEDLINEplus

[14] MEDLINEplus

[15] MEDLINEplus

pregnancy, a legal practice in the United States, and with legal precedence from the Supreme Court case Row vs. Wade.

Genetic Technology and Society

The director of the Life Sciences Project at Harvard Business School, Juan Enriquez, writes, "Perhaps the most important discovery of the twentieth century was to learn to identify and read the code of life. And perhaps the most important challenge we will face in the twenty first century . . . is how . . . and when . . . to apply this knowledge." [16] Genetics is an extremely powerful tool, the blueprints of life itself. Gregor Mendel's work with pea plants in the 1800's, Watson and Crick's discovery of DNA, and advancements in genome technology have led us as humans to a new era in biology. This new era in biology is a very volatile one; we as a people have many difficult ethical questions to answer with the advent of these powers. Thomas Shannon writes, "Two important factors must be kept in mind in evaluating or using any genetic testing technologies. First, while literally thousands of genetic anomalies can be detected, we understand the health implications of only few of them. Second we cannot cure any of the genetic anomalies that we detect."[17] We need to be extremely careful with the decisions we make while using information gained from genetic screening. One of the major problems with all of this knowledge is that while it is created to be used for good, there is no telling what the information in the hands of someone else might do with it. This is why there is such a heated debate over genetic issues, the positive characteristics coupled with a new technology might be overlooked because of the possible negative

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[16] Juan Enriquez, As The Future Catches You (New York: Crown Business, 2001), 72.

[17] Thomas A. Shannon, Ethical Issues in Genetics, Theological Studies: 1 March 1999.
<http://www.highbeam.com/library/doc3.asp?docid=1G154479979>

uses. We as a people need to take it upon ourselves to become informed in this area, so that fears about the possibilities of a technology do not overshadow the very real benefits that the technology provides for us.

Genetics Shape Our Lives

Genetics have been a very important part of our lives much longer then most of us actually realize. We have been breeding horses to be stronger and able to withstand long journeys for centuries. Dogs are not naturally house pets; they are naturally wolves. We genetically engineer crops to ripen slower so they can be shipped further and have a longer shelf life. We genetically alter crops so that they contain anti-oxidants. *"Genetic knowledge helps keep most of us alive. In 1804 there were one billion people on the planet . . . 1927 two billion . . . 1999 six billion . . . we would have starved long ago . . . If agricultural productivity had not increased much faster than population."* [18] People rarely think of the advancements in agriculture being direct results of genetic advancements. We as a human race are extremely dependent on genetics. If people had said long ago that genetics should not be tampered with because it is a power reserved only for God, then we might be living in very different times because of food shortages. There is no doubting the awesome power of genetics, and as long as we can continue to move cautiously and meticulously analyze every part of a new technology, we as a people can move forward into an era where genetics do not control our everyday lives, rather is a tool we can use to ease the state of being.

The Hippocratic Oath

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[18] Enriquez, 75.

Doctors too have difficult choices to make concerning genetic technologies. The Hippocratic Oath was written millennia ago, and at that time medicine was only done ex vivo. Now that genetics has become such an important science, a lot of research and treatment is done in vitro. Doctors and physicians use the Hippocratic Oath as a guide, however, this "new" biotechnology is making ethics a topic of debate. The Hippocratic Oath says:

> *"I swear by Apollo Physician and Asclepius and Hygieia and Panaceia and all the gods and goddesses, making them my witnesses, that I will fulfil according to my ability and judgment this oath and this covenant:*
>
> *To hold him who has taught me this art as equal to my parents and to live my life in partnership with him, and if he is in need of money to give him a share of mine, and to regard his offspring as equal to my brothers in male lineage and to teach them this art - if they desire to learn it - without fee and covenant; to give a share of precepts and oral instruction and all the other learning to my sons and to the sons of him who has instructed me and to pupils who have signed the covenant and have taken an oath according to the medical law, but no one else.*
>
> *I will apply dietetic measures for the benefit of the sick according to my ability and judgment; I will keep them from harm and injustice.*
>
> *I will neither give a deadly drug to anybody who asked for it, nor will I make a suggestion to this effect. Similarly I will not give to a woman an abortive remedy. In purity and holiness I will guard my life and my art.*
>
> *I will not use the knife, not even on sufferers from stone, but will withdraw in favor of such men as are engaged in this work.*
>
> *Whatever houses I may visit, I will come for the benefit of the sick, remaining free of all intentional injustice, of all mischief and in particular of sexual relations with both female and male persons, be they free or slaves.*
>
> *What I may see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself, holding such things shameful to be spoken about.*
>
> *If I fulfil this oath and do not violate it, may it be granted to me to enjoy life and*

> *art, being honored with fame among all men for all time to come; if I transgress it and swear falsely, may the opposite of all this be my lot."*[19]

This oath has served medicine well for a long time. One of the most basic tenants of the oath, which is to help and not to harm, can be used to mold the ethical views of the "new" biotechnology and medicine. There is no doubting the potential for harm using genetics; in fact, you cannot discount anything from happening because it really has not happened yet. The first thing that the Hippocratic Oath says is that the doctor is not to cause any harm to the patient. However, when there is debate over whether the therapy or technique is harmful, it then falls into the hands of the physician and the patient to determine what is best in a given situation. This is exactly why the oath is used in the first place, to protect the rights of doctors and patients to have the best care possible. That is like if a surgeon was not allowed to use a scalpel because that scalpel in the wrong hands could case serious harm. Keep in mind that not all medical doctors who take the Hippocratic Oath become surgeons it is just an example. All doctors are given the power to change people's lives immensely, and the oath is a guide to help them use this power wisely. That statement may seem like an extreme stretch of the imagination, ignorant, and an oversimplification of the issue; sticking to the main tenant of this argument, that we need to educate ourselves better before we pass judgment, makes that statement an easy way to show how lack of knowledge is detrimental to medical advances.

This relates to prenatal genetic screening for a myriad of reasons. There is serious debate over the societal harm prenatal genetic screening can cause, let alone the fact that

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[19] PBS Website, The Hippocratic Oath, trans. Ludwig Edelstein (Baltimore: John Hopkins Press, 1943), < http://www.pbs.org/wgbh/nova/doctors/oath_classical.html>

amniocentesis can cause a miscarriage.[20] However, it is also in the best interest of the patient to have a prenatal genetic screening test done when the mother is in a high risk category. Therefore it becomes an ethical debate as to whether or not the treatment is too harmful to society on the whole. The Hippocratic Oath does not contain the answer to this ethical quandary; however, it does show how difficult this debate is because a medical guide used for millennia does not provide a clear answer.

Genetics and Privacy

"We are learning the language in which God created life . . . without a doubt, this is the most important, most wondrous map ever produced by humankind."[21] This is an excerpt from the speech President Clinton gave announcing the assembly of the human genome sequence. President Clinton hit the nail on the head with these words. Mankind has been given an amazing power. This power is so great that it could quite possibly cause the downfall of our society. The President's Council on Bioethics calls biotechnology a form of human empowerment. In truth it is. Now that the human genome has been mapped, it is only a matter of time before we can exert amazing control over the human form. Imagine a future in which there is no disease, there is no such thing as misfortune or bad luck such as getting cancer because of the genetic control we can exert on our own genome. Some people think of this kind of a future and their minds immediately go to futuristic visions like Aldous Huxley's Brave New World or movies like "Gattaca" where the society has a genetic "class" system and people are divided by the genes that they are born with. These thoughts are natural reactions, and are good to

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[20] MEDLINEplus, Online ed., s.v. "amniocentesis.
<http://www.nlm.nih.gov/medlineplus/ency/article/003921.htm>

[21] Enriquez, 88.

have as a people. It will help to make sure that when these technologies become more commonplace, that our privacy is not invaded. If we do not control the way that technologies are used then we will be under control of the very things we are just beginning to learn how to control, our genes. This argument is not trying to make all genetic technologies out to be good. In research, they are all intended for good use, and good use meaning that they are made to help cure diseases, genetic disorders and to promote general well being. If we educate ourselves about each new technology that is discovered and tested, we can then decide how and when it should be used to make sure that we do not lose control to our genes. An example of this, which is a very real and is something that could very well happen, involves our medical insurance companies. Right now, there are biomedical companies developing microchips and genetic tests that will literally be able to screen your body for several thousand defects in a matter of seconds. This is both a good and a bad thing, much like the genetic technologies discussed in this paper involving fetuses. The good side of this would be that with one drop of blood and a matter of seconds your doctor can more easily determine how to help you. The bad side of this is that the insurance companies can also use this information and invade your privacy. *"In most instances people seek medical services because they are already ill. But with predictive genetic testing, there may be an incentive for biomedical companies and physicians to market such tests heavily, and healthy people interested in learning whether they are at risk for later diseases may not consider the psychological, social, and financial impact of learning genetic information before they agree to genetic testing."*[22] Even today, biomedical companies market preventative procedures such as full body

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[22] Lori B Andrews, Future Perfect (New York: Columbia University Press, 2001), 5.

MRIs.[23] Andrews then also goes on to add that there would be a "therapeutic gap" and that insurance would be based upon genetics. This is something that Enriquez also talks about to great lengths in As The Future Catches You. The "therapeutic gap" discussed is where patients who have a certain mutation in their genes might be denied insurance or have a higher premium because it could be considered a pre-existing condition. Here is a case where these technologies are going to be available very soon, and we as a people need to embrace them, and control them.

Privacy is a very important thing to people. We value our right to private property and our personal freedoms protected by the constitution. However, with the influx of new genetic technology, there is a growing fear that the medical information privacy laws may not be broad enough to encompass genetic information. Genetic information is easily obtainable, and we are constantly shedding material containing genetic information in our hair, saliva and blood.[24] People fear that this information can be used against them to discriminate against certain genetic pre-dispositions in the workplace and for insurance. There are a few laws in place currently that protect our privacy regarding medical information. However, these laws are not broad enough to adequately protect our information in the future.

Thomas Shannon identifies three types of privacy. Physical privacy is defined as *"freedom from physical contact."*[25] Informational privacy *"limits access to information*

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[23] <www.vitalimaging.com>

[24] Lisa M. Caperna, The Brave New World is Here: Privacy Issues and the Human Genome Project: Governments and Courts Must Step in to Provide Protections and Regulations for the Use of Individuals' Genetic Testing Results, Defense Counsel Journal: 1 January 2003. <http://www.highbeam.com/library/doc3.asp?DOCID=1g1:9773005&num=4>

[25] Thomas A. Shannon, Ethical Issues In Genetics, Theological Studies: 3 March 1999. <http://www.highbeam.com/library/doc3.asp?docid=1g1:54479979

about one's self."[26] And, decisional privacy *"the capacity to make decisions for one's self."*[27] Both genetic screening and prenatal genetic screening can affect all three types of privacy. Considering genetic information, *"from a privacy perspective, two things are clear: 1) people are afraid of genetic testing and 2) genetic information has been used to hurt people rather then to help them."*[28] Goldman indicates four areas that need to be considered to protect the privacy of genetic information. The first involves access: *"who should have access to a person's genetic information, under what circumstances and for what purposes?"*[29] The second is use: *"how should those who obtain a person's genetic information be allowed to use it?"*[30] The third is disclosure*: "to whom should those who obtain/create/receive genetic information be allowed to disclose it, and for what purposes?"*[31] And, the fourth consideration is storage/security: *"what safeguards and safety precautions should be in place to make sure that genetic information is not obtained, used or disclosed inappropriately?"*[32] This is therefore why the issue of privacy and genetic information is a very hot ethical debate, especially in the case of prenatal genetic screening, where the patient who has not even been born yet cannot make consent about genetic information. Prenatal diagnosis of a fetus immediately makes the health and genetic status of the fetus available to medical and insurance professionals. This information can limit what the mother and her fetus are able to do

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[26] Shannon, Ethical Issues In Genetics.
[27] Shannon, Ethical Issues In Genetics.
[28] Janlori Goldman, Genetics and Privacy, American Journal of Law & Medicine: 22 June 2002. <http://www.highbeam.com/library/doc3.asp?DOCID=1G1:99746967&num8>
[29] Goldman, Genetics and Privacy.
[30] Goldman, Genetics and Privacy.
[31] Goldman, Genetics and Privacy.
[32] Goldman, Genetics and Privacy.

because an insurance company could deem any condition preexisting and therefore not cover any medical procedures or care.[33]

"*. . . Americans cannot be assured that their DNA will not be taken or used against their will or without their knowledge. The United States has no coherent policy for whether, when or how genetic testing should be encouraged, facilitated, discouraged or prohibited. Instead, we have policies and practices that impact some people, in some places, under some circumstances. This kind of weak patchwork leaves gaping holes.*"[34] The United States has some policies and laws that are in practice right now that may cover the privacy of genetic material, such as the Health Insurance Portability and Accountability Act (HIPAA),[35] [36] Titles VII of the Civil Rights Act of 1964,[37] and the Americans with Disabilities Act of 1990.[38] [39]

HIPAA states that genetic information cannot be considered as a preexisting condition without a physical diagnosis of the actual condition. That means that a person who tests for a mutation that is known to be a predisposition for breast cancer, cannot be considered to have breast cancer until that person physically has breast cancer. However, HIPAA is limited because it does not protect people from a rate increase due to genetic testing results. It does not protect people who are in a group plan from discrimination, and it does not protect against discrimination in the workplace. Title VII stops employers from discriminating based on sex, race, national origin, religion, or color. Title VII was used to defend African-Americans from pre-employment screening for sickle-cell anemia

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[33] Shannon, Ethical Issues In Genetics.
[34] Goldman, Genetics and Privacy.
[35] Goldman, Genetics and Privacy.
[36] Caperna, . . . Brave New World . . .
[37] Caperna, . . . Brave New World . . .
[38] Goldman, Genetics and Privacy.
[39] Caperna, . . . Brave New World . . .

without their consent (see Norman-Bloodsaw v. Lawrence Berkeley Laboratory). Title VII is also limited, however, because the majority of genetic conditions are not linked to ethnicity, race, or sex.[40]

"Under the ADA, a person with a disability is defined as one who either (1) has a physical or mental impairment that substantially limits major life activity, (2) has a record of such impairment or (3) is regarded as having such an impairment."[41] However, the ADA does not specifically address genetic or prenatal genetic testing. All three of these acts leave people wondering how their privacy is going to be protected by the government.

Right now, two bills before the 107th Congress are set to amend HIPAA and ADA. The Genetic Nondiscrimination in Health Insurance and Employment Act, introduced by Senator Thomas Daschle, S.318, and Representative Louise Slaughter, H.R. 602, in February 2001 is designed to build o HIPAA by limiting health insurers and health plan access to genetic information. The Genetic Information Nondiscrimination Act, S.1995, introduced by Senator Olympia Snowe in March 2002 is designed to limit access to genetic information. Goldman calls S. 1995 a failure because even though it is designed to limit access to genetic information, it does not.[42]

S.318/H.R. 602 builds upon the HIPAA and the ADA by adding more regulations regarding privacy. The basic tenants of S.318/H.R. 602 are:

> *"Prohibiting group health plans and insurers from requesting or requiring that individuals undergo genetic tests;*

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[40] Caperna, . . . Brave New World . . .
[41] Caperna, . . . Brave New World . . .
[42] Goldman, Genetics and Privacy.

> *Prohibiting group health plans and insurers from requesting or requiring individuals to provide protected genetic information, with limited and stated exceptions;*
>
> *Prohibiting group health plans and insurers from disclosing protected genetic information to employers;*
>
> *Prohibiting the use of protected genetic information for medical underwriting in the individual insurance market and in those aspects of the group market not addressed by the nondiscrimination provisions in HIPAA;*
>
> *Directly regulating employer acquisition, use, disclosure and storage of protected genetic information; (70)*
>
> *Creating a private right of action for people whose rights are violated, whether by group health plans, insurers or employers; (71)*
>
> *Applying specific disclosure prohibitions to certain group health plans that are not reached by the HIPAA privacy regulation; and*
>
> *Confirming that group health plans and insurers cannot disclose protected genetic information to the Medical Information Bureau (MIB).*"[43]

These regulations seem adequate to protect the privacy of the patient regarding genetic information. However, nowhere is prenatal genetic screening specifically mentioned. There needs to be specific language added to these or future bills so that the rights and the privacy of both the fetus and of the mother are not abused.

What is Prenatal Genetic Screening?

Since the discovery of the DNA molecule, the idea of controlling genes through insertion or modification to create better people has been a thought. However, until recently it has not been too much of a possibility. Now, the idea that *"'designer babies,' children born with improved genetic endowments, the result of either careful screening and selecting of embryos carrying desirable genes, or of directed genetic change*

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[43] Goldman, Genetics and Privacy.

("genetic engineering") in gametes or embryos," [44] is becoming more relevant in today's society. Parental genetic testing has been used for nearly 30 years to asses the health of the fetus.[45] Not only is it used to test for serious disorders, but also less serious disorders; diseases that manifest at birth, and diseases that manifest later; Andrews also writes that it can test for Huntington's disease, breast cancer and homosexuality.[46] Genetic testing can aid in clinical decision making by providing diagnostic and prognostic information.[47] It raises many fears among people. They fear technology like pre-natal genetic disease screening could lead to a race of designer children, whose entire genetic makeup was pre-determined by their parents. To think of such a thing ignores the very technology involved in pre-natal genetic screening. Pre-natal genetic screening by amniocentesis or chorionic villius does not control or change the genes that the fetus has. Pre-natal genetic screening can only use markers for known genetic sequences to find mutations in the fetus that cause diseases. *"A genetic test is, 'the analysis of human DNA, RNA, chromosomes, proteins, and certain metabolites in order to detect inheritable disease-related genotypes, mutations, phenotypes, or karyotypes, for clinical purposes' "*[48] It is a widely used practice in medicine among older pregnant women, and women who are considered to be at high risk for mutation. The conclusion by The President's Council On Bioethics is, *"prenatal diagnosis and selective abortion, widely practiced since the 1970s in order to prevent the birth of children with genetic or chromosomal abnormalities, is a weeding-out procedure; hence its potential to select "better than*

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[44] The President's Council On Bioethics, Beyond Therapy: Biotechnology and the Pursuit of Perfection, 2003 (Washington, D.C., October 2003) Chapter 2, Page 2.
[45] Andrews, 4.
[46] Andrews, 5.
[47] Wylie Burke, "Genetic Testing," The New England Journal of Medicine 347 (December 5, 2002): 1867.
[48] Burke, 1868.

normal" babies is negligible, and it is unlikely ever to be effective or widely used for such purposes." [49] For parents who are trying to achieve a pregnancy with a child who has better features to use genetic screening and abortion to weed out pregnancies with unwanted genetic characteristics is not very likely. It would take many trials and errors, and the risks involved in abortion are just not healthy to the mother. Also, there is no way that the child would ever end up with traits better than what either of the parents can donate to the child because the pregnancy is conceived naturally.

There are several medical benefits to pre-natal screening. The first is that a family who was going to be burdened with a child whose life was to be short, painful and economically difficult because of a genetic disorder will have the option to forgo that trauma and opt to abort the pregnancy. Diseases like Tay-Sachs can barely be treated, and the life of the patient is not a very bearable existence. Because of the advent of genetic screening, couples who in the past would have chosen not to have children, because they are at high risk, can try because they can find out if their fetus has serious genetic defects. Another medical benefit is that it is the almost purest form of preventative medicine. By screening for genetic diseases and then eliminating affected fetuses, eliminates the need to ever have to treat that patient. [50]

Prenatal genetic screening is an ever-improving technology. Recently there have been many advances. *"A new parental technology, fetal cell sorting, provides information about the fetus without creating the physical risk to the fetus or the pregnant woman that is caused by amniocentesis or chorionic villi sampling (CVS). A blood test is performed on the woman, and complex procedures in the laboratory capture minute*

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[49] The President's Council On Bioethics, Chapter 2, Page 4.
[50] The President's Council On Bioethics Chapter 2, Page 5-6.

amounts of fetal blood cells that are circulating in the woman's blood."[51] These tests can screen for many genetic disorders, Down's syndrome, Cystic Fibrosis, and Tay - Sachs disease to name a few. These are genetic diseases for which there is no cure, and some of which are terminal. We have to look at this side and see how important this is to medicine. Parents have the right to know this kind of information before they give birth, and doctors should know so that when new technology becomes available that they could possibly begin treating the patient as a fetus.

Genetic screening does raise a few societal concerns however. The practice of *"negative eugenics . . . elimination of the genetically unfit and a reduction in the incidence of their genes"* [52] is considered. This is not exactly the case in genetic screening because genetic screening is done on a case-by-case basis, and it is not mandatory that the pregnancy be terminated or that the fetus is screened for diseases. However, this point does lead into other areas of societal concern. The major societal impact that genetic screening may have is that the value of human life may change. No longer would life be guaranteed upon conception; rather a standard would have to be met in order to be brought to term. People might see others with genetic defects as mistakes, and the fault of the parents for allowing a child with a genetic disorder to be born. Even today, a parent whose child is born with Down's syndrome may be asked if they had an amino test done or how that the child was born. This kind of a change in society is something that is already happening, and is not a cause for concern. The futuristic movie *Gattaca* portrays a very technologically accurate future of what could happen if the spectrum of genetic screening is broadened to things that may be genetic defects, but are

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[51] Andrews, 10.
[52] The President's Council On Bioethics, Chapter 2, Page 6.

manageable in life. The thing that people have to remember above all else, is that in a movie like this, there are more controls over birth being used than a genetic screen; there is also genetic engineering at work.[53]

The grouping of genetic engineering and of genetic screening is often common and damaging to the image of genetic screening. They are in fact two very different technologies. Genetic engineering is a very volatile science that allows for the insertion, modification, or deletion of genes into a fetus, embryo, or adult to create a desired change. Genetic screening is testing for markers in genes that are already present, and in the case of pre-natal screening using amniocentesis or chorionic villius the parents are then given the choice to abort the pregnancy or to carry it to term based on the findings. Genetic screening can not lead to a race of super-humans, the genetic control it exerts over people is nowhere near broad enough to do so. Even the fear of designer babies is ignorance about the technology being used. Genetic screening is a very necessary technique and with time, as the technique is further perfected, will be routine medical work for all pregnant mothers.

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[53] The President's Council On Bioethics, Chapter 2, Page 6-16.

Pro Argument

Potential Gained from Prenatal Screening

The purpose of medical technology is to better the quality of human life. One of these technologies that is available to humans is prenatal genetic screening. The ability to recognize genetic defects while the fetus is still in the womb is important and must be continued because it may some day lead to the development of technology that can prevent the defects that are detected. To stop genetic screening would mean to also stop the development of any such technology. In comparison, if people felt that blood work was in someway unethical and successfully campaigned to have it stopped long ago, we may not have any of the vaccines today that save millions of lives. People would not have the understanding of the human immune system and how it is connected to the white blood cells, and it is in this same logic of thinking that we can hope that there is potential for some medical breakthroughs that will someday surface through the use of prenatal screening.

Imagine if someday technology could be developed that would allow us to correct such genetic disorders as sickle cell anemia, Down syndrome, or Tay-Sachs syndrome. The amount of lives saved by such a technology would pile up very quickly, and it would be a tragedy if all these lives that could be saved were lost because some people feel that detecting diseases and disorders prenatally is unethical. The connection between connecting and curing these disorders is not explicit, but it is in the same way that blood work somewhat led to vaccines that we could hope that prenatal screening could in some way lead to the correction of these disorders.

One could also argue that the technology could still be developed without having prenatal screening in the general public. This is probably true, but if the technology to fix these genetic disorders is to be developed, it will come a lot sooner if it is kept on the "front burner". Any lives lost during the delay between the time that it was recognized in this way and the time that it could have possibly been recognized with screening allowed in the public would be lives that could have been saved.

Another argument against prenatal screening would be that this would be another example of humans trying to play god. Though it is an example of genetically altering humans for the better, even those who oppose the idea of prenatal screening must agree there is a world of difference between making someone not have Down syndrome and altering someone to be taller. Even more extreme is the case were a live can be saved by preventing a fatal disorder.

Again it comes back to the purpose of medical technology, which is to better the quality of human life. This definition can be taken a step further to differentiate between preventing and fixing problems, to simply improving a human body that does not need fixing. To say that this is like playing god by altering genes may be true, but sometimes it must be allowed. It is the same as plastic surgery to alter the human appearance, which some may view as unnecessary. However, plastic surgery is viewed in another light when it used to alter the appearance of a severe burn victim, or reconstruct someone's face after a car accident. The same is the case for genetically altering humans. Though it has the potential to give humans the capacity to make unnecessary changes to genes to improve humans, the technology must be pursued and developed because of its potential to save human lives.

The Importance of the Detection of Fatal Genetic Disorders

The most painful news an expectant parent could receive would be that their unborn fetus has a fatal disorder. But this is a reality. It does happen. Even more painful would be to deliver the baby, then receive the sad news amongst the happiness that radiates from the birth of a newborn baby. This situation can be avoided by having the fetus genetically screened while still in the womb. With a fatal disorder, it is almost certain that parents would want to know before they deliver the child. Even those who oppose prenatal screening must concede that it would be almost cruel to the parents to deny them this knowledge when the technology exists, and is relatively safe.

The risks that the mother face vary from procedure to procedure, and none of the procedures are considered overly dangerous. Some involve of the more risky procedures involve penetrating the uterus with a long needle, and the risk is more to the fetus then to the mother. The safest are simple ultrasound scans, which really pose no threat at all to neither fetus or mother.

Just as in the case of non-fatal disorders, the decisions the parents make after the test is performed must be dealt with separately. With fatal disorders, the life of the fetus is not looked at in the same way as with a non-fatal disease, especially in the case of those disorders where the life expectancy is very short, such as Tay-Sach's Disease. Some mothers may question whether it is worth the risk to themselves to carry and deliver the baby if it is only going to live a few days or weeks. It must be remembered that pregnancies last nine months, and if the screening is performed early in the pregnancy, that means the mother going through months of the hardship of pregnancy to birth a child that will not live more than a few days in some cases. These are very emotional and difficult situations to discuss, but they are real, and ethical guidelines must be laid out for them. It must be ultimately left up to the parents and especially the mother, as it is her body that is at risk during pregnancy. The most important rule that must be taken from all this is that the option to have screening performed that could allow them to know about a fatal genetic disorder before birth must be given to the parents.

Fatal disorders are rare, but it would be unfair and unethical to deny the unlucky few parents whose child has a fatal genetic disorder the option of screening just because it is very uncommon. It is these very people who concretely secure genetic screening in the area of ethical medical practices. People could argue that it doesn't matter what disorder a fetus has; the parents don't have the right to know about it because it might lead to them denying the fetus a chance to be birthed. If that argument can be put aside, those same people must agree that genetic screening is ethical because of those with fatal genetic defects, because early termination of the pregnancy becomes a much more reasonable option.

The Importance of the Detection of Down Syndrome and other Non-Fatal Disorders

The most common major defect detected by prenatal screening is Down syndrome, at an average of about 1 in 700 births. It is also probably responsible for the most controversy surrounding prenatal screening because of its nature. It can lead to mental retardation, ranging from mild to severe, medical complications such as heart malformations, and complete degenerative dementia after age forty. Though those are all terrible conditions, Down syndrome in itself is not fatal. So if a parent chooses to terminate a pregnancy because genes that cause Down syndrome were detected, the test has led to the loss of a potential human life. This is one of the main platforms of those who oppose prenatal screening. People do not view the situation the same way if a parent chooses to terminate a pregnancy because the fetus was found to have a fatal genetic disorder, because if the baby was born, its life may be short and sad, and no doubt a very painful experience for all those involved. There are also some disorders, such as cystic fibrosis, which are eventually fatal but may take many years to come into effect. Those will be discussed another time, as we focus our attention on disorders like Down syndrome.

If the option to have genetic screening performed was taken away from future parents, they would of course be surprised when they gave birth to a baby with a condition like Down syndrome. It is unnecessary to discuss the sadness of the situation that would most likely occur, but it is important to look at the practicality of the situation. The will be completely unprepared both mentally and as far as there living conditions to raise a mentally retarded baby. If they had the option of genetic screening and turned it down, then they don't have anything to complain about in that respect. It is the couple who would have had the screening performed that is affected. The purpose of medical science is to better the health and quality of life for human beings. To deny people the option to have genetic screening performed would be to hurt their quality of life in many ways. An argument against this point would be that genetic screening denies fetuses the right to life because the results can cause the parents to terminate the pregnancy. It is important to keep separate the argument of abortion and genetic screening, though they are inherently connected because people who oppose genetic screening usually do so because it leads to abortion. If people believe that abortion is bad then that is what they must oppose. Still some groups directly relate the two topics. The Society for the Protection of Unborn Children makes the point that *"...abortion of the handicapped is both a reminder of the inhumanity of abortion, attacking the most vulnerable, those most in need of help, and an offence to the disabled, sending them the message that they are inferior and of less value than the able bodied"*[54].

In the United Kingdom this situation is more explicitly defined, as the Abortion Act of 1967 makes it so that abortions can only be carried out after a certain time for certain reasons, and it is up to the doctor, not the patient, to decide if the situation is dire enough to allow an abortion. Still, *"Rather than wanting to 'play God', many doctors would prefer it more specific guidelines were drawn up to guide them when they make decisions about whether a request for an abortion on the grounds of fetal abnormality is legal."*[55]

Genetic screening hurts absolutely no one, and helps all those involved. It eases the worry of the parents of a baby with nothing wrong with it. It can allow the parents of a Down syndrome baby to make preparations that will be needed so that they can effectively raise their child. And if the parents decide to terminate pregnancy based on the results, that decision, just as the decision to get screening done, is theirs, and must be

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[54] SPUC. Undated. 'Our aims, ethics and activities'. London: SPUC.

[55] Chervenak, F. A., McCullough, L.B. and Campbell, S.. 1995. 'Is third trimester abortion justified?' *British Journal of Obstetrics and Gynaecology* 102 (June):434-5; Green, J.M. 1993. 'Obstetrician's views on prenatal diagnosis and termination of pregnancy: 1980 compared with 1993'. British Journal of Obstetrics and Gynaecology 102 (March): 228-232

opposed on a separate level than the screening. It must still be acknowledged that in most cases, if the fetus is found to have Down's syndrome, the pregnancy is aborted. The overwhelming majority of women who discover that they are carrying a fetus affected by Down's Syndrome currently choose to have an abortion. A study by ante-natal screening expert Professor Eva Alberman shows that just eight per cent of women who discover they are carrying a fetus affected by Down's syndrome decide to continue the pregnancy[56]. It is important to remember that many of the pregnancies that are terminated are fetuses with no genetic disorders at all.

The Decision to Have Screening

Most women who are pregnant would agree that the main burden of the pregnancy is on their shoulders. They are responsible for carrying the baby from zygote to fetus to hopefully about an eight pound infant. This can put both a tremendous physical and emotional strain on the woman's body and mind over this nine month period. In addition to the dramatic physical changes that are taking place, the new hormone imbalances that are present as a result of the pregnancy can cause many women severe stress and anxiety. In a lot of cases this anxiety is about the successful pregnancy. Sadly, however, not all pregnancies will be successful.

Down syndrome will occur in 1 in 700 babies (in the United Kingdom) on average. This average can be broken down further, as the rate rises along with the age of the expectant mother, from 1 in 1,000 when the mother is 28 to 1 in 200 when the mother

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[56] Alberman, E. Mutton, D., Ide, R.G.. 1998. 'Trends in prenatal screening for and diagnosis of Down's syndrome: England and Wales, 1989-97'. *British Medical Journal*

is 38.[57] Most people would probably consider 1 out of 1,000 a safe bet, but as the rate approaches 1 in 200, mothers must start to worry, and any worry and anxiety that a mother would have about this must be multiplied by her hormone imbalances during the pregnancy.

Some people would choose not to do something if they fear regretting the decision if it turns out badly.[58] To take this logic a step further, some mothers would not get tested for fear of learning that their baby has a genetic disorder. One must remember though, it is not the test that determines the result of the pregnancy. The result is set regardless of whether or not the mother is tested, and in most genetic cases, no one can do anything about it except terminate the pregnancy. It is this fear, that the test will lead to the termination of the pregnancy, which causes many people to oppose prenatal screening.

> *"The secular ethical issues raised by genetic testing and screening fall into three major categories: issues concerning education and counseling; problems involving confidentiality, and issues of justice. Some writers assert that genetic ethical issues are no different than those in other bioethical situations and that the new genetic technologies raise no new ethical questions for physicians or patients. Even if that is so, there are a number of factors, inherent in genetics which should heighten our sensitivity to the human values involved". These factors include our ability to predict diseases which cannot be treated or cured (e.g., Huntington's disease); ambiguities in the concept of genetic disease (Does a gene carrier for a recessive disease have a genetic disorder? Is a person who will later develop Huntington's disease ill?); poorly understood concepts of genetics and risk by the public; the potential for injustice because of racial and ethnic differences in genetic diseases; the intimate relationship between genetic inheritance and personal identity (genetics ties us to our ancestors and our descendants); the fact that genetic information also affects others, especially family members;* ***and the disproportionate***

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[57] Conflict and Tradeoffs in Decision Making; edited by Elke U. Weber, Jonathan Baron, and Graham Loomes; Cambridge University Press; © 2001; pg 157.

[58] Ibid; pg 156.

burden on women in screening, choice to abort or not abort, and the consequences of that choice."[59]

The decision must be left up the mother, if not to both parents. Abortion debating aside, it is the mother's right to know exactly what is going on inside her body. It would seem extremely unethical to tell a person that they cannot be told something about what is happening to them. This is especially true in cases where the risk is high, such as when both parents carry recessive genes for of a disease, or when the mother is older than usual. A situation like that could lead to extreme anxiety for the parents. Though a test result of positive would certainly be sad, it is better than the anxiety and stress that it would replace for two reasons. One is that sadness about an event can be similar to mourning, something that is unimaginably bad, but one will eventually move on and get over. Anxiety and stress can be unhealthy, and can make people unable to function as they normally would. Again all these things are multiplied by a woman's hormone imbalance during the time of pregnancy. To make things worse, if their fears were confirmed by delivering a baby with a genetic disease, especially a fatal one, they would have the period of sadness anyways, and it would most likely be very much worse. The second reason a test result of positive would be better would be that it would allow the parents to make some decisions that they would not have had a chance to make otherwise, as well as make necessary preparations if they decide to continue with the pregnancy. Some genetic diseases can be simply accepted and the birth of a child would be a great event for the new family, now that they expected it anyways, where as if they did not expect the birth would certainly be a sad event.

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[59] Murray TH, Botkin JR. Genetic testing and screening: ethical issues. In: Encyclopedia of Bioethics (WT Reich, edit.), revised edit. New York, Simon & Schuster Macmillan, 1995, Vol. 2 pp. 1005-1011.

The option to have genetic screening should never be taken away from a mother. The debate should instead be whether or not they should be required for mothers at higher risk. A study conducted by Rosemary Murray and Jane Beattie took forty mothers and offered them the Triple Test, which tests for Down syndrome, anencephaly, and spina bifida. Of the forty, thirty six accepted and four declined. The following are reasons given by the women for why they accepted or declined the test (number of women who made that claim in parenthesis)[60].

Accepted:

- "For peace of mind" (7)
- "It's a harmless blood test, there is no reason not to" (7)
- "To be able to have a termination if something is wrong" (6)
- "To be prepared for the birth of a handicapped child" (6)
- "I want to have as much information as possible" (5)
- "It will give us an option if things are wrong" (5)
- "Simply because its there" (2)
- "For research purposes- to benefit the medical profession (1)
- "The doctors seem to be advising it" (1)

Declined:

- "There is no point, as I wouldn't have a termination" (2)
- "I don't want the worry of it all, I would rather have a happy pregnancy" (2)
- "I would rather not know that have to make the decision of whether or not to have a termination at 24 weeks" (2)
- "I just don't want to" (1)
- "I might be forced into making a decision I am not happy about making" (1)

The results show that many of the women claim the worry as a part of there decision of whether or not to have the test performed, with the majority electing to have the test done. Even the women who choose not to are probably still worried, but they have negative views on abortion and worry that if the test was positive they would want to have one, so they would rather just not know.

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[60] Conflict and Tradeoffs in Decision Making; edited by Elke U. Weber, Jonathan Baron, and Graham Loomes; Cambridge University Press; © 2001; pg 163.

Giving the women the option of prenatal screening is ethical, as it is itself is not only relatively safe, but as these women show, beneficial to the mental health of the women, which can become very fragile during pregnancy. The reason that some people see it as unethical is because it may lead to abortion. It must be understood that they must see the abortion as unethical, and not group the screening into the abortion. The decision to have the screening performed must be looked at as an isolated event, and in this sense there is really no negative to giving the women the choice to have test. As these tests results show, those who oppose abortion and fear that the test may lead them to have an abortion if the results are unfavorable can simply elect not to have the test themselves. It would be almost cruel and torturous to deny a woman who is carrying a baby that is at high risk for a genetic disease the right to know as soon as possible, if that is what she wants, and rather make her suffer in her stress and anxiety for nine months. The option to have screening performed is ethical and must not be denied to expectant mothers who elect to have it.

Prominent Pro-Prenatal Screening Opinions

The field of bioethics is like no other in biology. There is no black and white, right and wrong. This is because it is a field of opinions and beliefs, with no scientific process to determine what is the accepted proper way of doing things. There is only the acknowledged opinions of the experts, doctors authorities, and journals. They don't always agree of course, which is what sets bioethics apart from the other areas of biological study.

The American Journal of Public Health (3/87) said, *"Increasingly, prenatal diagnosis procedures and selective abortion are considered standard components of* *complete obstetrical care."* This leaves their position on the matter somewhat ambiguous, but they are acknowledging that the practice of prenatal screening is becoming accepted as a practice. The date on the article is somewhat old, and their stance may have since changed. Another thing to keep in mind about journals is that even though they are edited before they are published, they are still usually just a compilation of articles and reports from different authors, who may themselves take different views on subjects.

"During the past two decades, prenatal screening for fetal defects has become a standard part of nearly every pregnant woman's medical care" states Elizabeth Kristol, in her 1993 article "Picture Perfect: The Politics of Prenatal Testing"[61]. She further goes on to say *"Prenatal testing is eradicating illness in a whole new way-preemptively. In so doing, it is imperceptibly altering the pattern of disease in this country. It is changing society's fundamental attitudes toward parenting, toward sickness, and toward social responsibility. It is even influencing women's notions of childbirth, medicine, and motherhood."*

An interesting part in her article elaborates on the government views of prenatal screening, and its importance to health and society:

> *"Like the medical community, the public health sector has its own reasons for promoting widespread prenatal screening. The U.S. Department of Health and Human Services has announced a goal of screening at least 90 percent of the U.S. population "for fetal abnormalities," an objective that "will be measured by tracking use of maternal serum alpha- fetoprotein screening tests." The HHS report that explains this goal states that "current ACOG standards recommend that MSAFP screening be offered to all patients"-without noting that this was a legal, not medical, recommendation. Likewise, the California Department of Health, as part of its ambitious statewide screening program, requires everyone who offers prenatal care to inform pregnant patients of the AFP test in an effort to detect greater numbers of potential birth defects.* ***The fact is that governments on both the state and national level have considerable***

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[61] *First Things* 32 (April 1993) ©1993; pgs. 17-24.

> ***interest in being able to point to reductions in disease. And morbidity and mortality rates are key expressions of a region's standard of living."***

This shows the important step taking place of the government accepting and promoting a medical procedure. Of all the opinions and stamps of approval, it is probably the national governments that carries the most weight.

Some people take a colder look at the ethical discussion, but that does not make their argument incorrect. One of that most important parts of life is finance, and it has the ability to impact many situations that it would not normally seemed involved in. *"Policymakers and medical experts are under pressure not only to achieve noticeable improvements in health but also to reduce soaring health care costs. Widespread prenatal screening followed by abortion for fetal defects would accomplish both of these objectives."*[62] Some people may not like the lack of humanity in this argument, as it talks about abortion as if it an afterthought, but its accuracy must still be acknowledged. Surprisingly however, a lot of people would back this argument up. In a survey of British obstetricians in the late 1970s, researcher Wendy Farrant discovered that two-thirds of the respondents rated *"savings in costs to society of caring for people with disabilities"* as an important benefit of a national screening program for neural-tube defects; 13 percent agreed that *"the state should not be expected to pay for the specialized care of a child with a severe handicap in cases where the parents had declined the offer of prenatal diagnosis of the handicap"*.[63]

In 1983 the president formed a committee to draw up some guidelines for the public concerning genetic screening. The came to the conclusion that *"Genetic screening*

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[62] Kristol, Elizabeth; Picture Perfect: The politics of prenatal testing; © 1993

[63] ibid

and counseling are medical procedures that may be chosen by an individual who desires information as an aid in making personal medical and reproductive choices. Professionals should generally promote and protect patient choices to undergo genetic screening and counseling." It is committees like these that have set the guidelines for what is accepted in the past, and their approval is very important to the public opinion, because it is assumed that their research is the most complete and thorough that it can be.

Barbara Katz Rothman is a respected sociologist and has made her views on many debated subjects public, one of them being genetic screening. She in her discussion she talks about the value of information in making a decision, and how genetic screening is just another way to obtain information to fuel a decision. She states *"If there is information to be had, and decisions to be made, the value lies in actively seeking the information and consciously making the decision. To do otherwise is to 'let things happen to you,' not to 'take control of your life.'"* She also regards women who decline to have genetic screening done to have *"turning away from the value of choice, and even more profoundly, turning away from the value of information."*[64]

Angus Clark makes an interesting comment concerning the difference between having an abortion because of a genetic defect and having one because the pregnancy is simply unwanted. He finds it interesting that people argue so much about genetic screening because of abortion, instead of simply focusing on the abortion itself if that is what they have a problem with. This, Clarke says, indicates the *"low value that our society places upon those with genetic disorders and handicaps. We draw some moral lines for social but none for genetic termination of pregnancy."*[65]

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[64] ibid

[65] ibid

A good portion of the people and groups who actively discuss the ethics of prenatal screening are not groups founded on abortion or pregnancy issues at all, but rather ones that concern themselves with genetic issues like cloning and designer babies. One such group is the Council for Responsible Genetics (CRG). They take the view that genetic screening is okay the way it is now, but it still may put to much pressure on a pregnant woman. The backbone of their argument though is that if genetic enhancement becomes available, we must be extremely careful not to let the situation get too out of hand. *"Already, prenatal screening and pre-implantation diagnosis make it possible to eliminate fetuses and embryos with a number of identifiable genetic conditions. As disability rights activists point out, these developments put women in the position of "eugenic gatekeepers." Inheritable genetic modification, to whatever extent it turns out to be technically possible, would amplify the powers of eugenic selection many times over."*[66]

The idea that genetic screening may lead to out of control genetic altering is one direction of the argument pro-screening groups must fight, the other being the anti-abortion people who feel that the screening leads to the abortion of fetuses. There are still three smaller groups that make up this group, being people in the medical profession who oppose abortion and witness prenatal screening leading to the decision to have abortions performed, those who are involved with disability rights movements, and those who are simply hardcore anti-abortion. Each of these argue against it for different reasons, which all lead to three counter arguments.

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[66] Darnovsky, Mark; Human Germline Manipulation and Cloning as Women's Issues; GeneWatch; volume 14; number 4; ©2001

Issues like pre-natal screening, abortion, gene-manipulation and cloning are all things that make up the core of bioethics debate at this stage of our medical technology. There is no right or wrong though, and in most cases there never will be. The only way we will be able to tell is let things unfold and let technology evolve. Usually society will end up leaning one way or another, and until there is solid evidence or many hard examples of why one option is better than the other, the debate about these topics will rage on forever.

The Benefit of Prenatal Screening Outweighs the Risk

As with most medical procedures, there is a risk involved in genetic screening. This risk is compounded by the delicateness of a mothers body when she is pregnant, as well as the fragileness of the fetus. "As in all medical procedures, the benefit to be gained must be weighed against the hazards of the testing itself"[67]. In some situations, the parents may feel that there is not enough of a chance of there child being born with a genetic defect to warrant taking the risk of getting tested. Other parents however, such as older parents, ones who previously gave birth to children with genetic defects, or parents who know to be recessive carriers of a genetic disease themselves, would probably always opt to have screening performed. The choice must be left up to each set of parents on an individual basis, after proper consultation with their obstetrician. The important thing that the parents must know is that if they are healthy, the risks involved with getting screened our out gained by the rewards, or to be put another way, less than the undue physical and emotional trauma that could be suffered if they choose to forgo the screening, and their child is born with a genetic defect.

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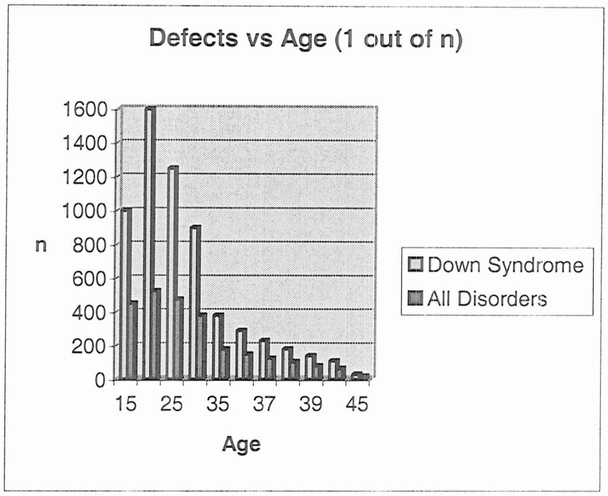
[67] Jackson, John F., MD; Genetics and You; © 1996; pg. 27.

There are some cases were this idea is not even a question. One is when the mother is older than 35. Below is a chart showing the rates for both down syndrome and all genetic defects as the age of the mother increases.

Age	Down Syndrome	All Disorders
15	1000	450
20	1600	525
25	1250	475
30	900	380
35	380	180
36	290	150
37	230	125
38	180	105
39	140	80
40	110	65



As the chart shows, the likelihood of having a disorder free birth drastically decreases as the age of the mother increases.

There are different methods for performing screening tests on fetuses, some are more invasive and risky than others. Usually the invasiveness of the procedure can be correlated to both its accuracy and the range of disorders it can detect. It is important for a mother to know what specific disorders she is at risk for, because she may only want to go as far as needed to be tested for them, and be able to skip tests that put her at higher risk.

The simplest and least risky type of screening is a sonography. This is simply and ultrasound procedure, where an image of the fetus is obtained without invading the womb through use of sound waves. The procedure is harmless to both mother and fetus, and is completely painless to the mother. The downside is that the only disorders than can be seen are ones where there are obvious physical abnormalities. It is because of this that it is useful for detecting neural tube defects, such as spina bifida and anencephaly. The quality of the image varies from ultrasound to ultrasound, and under ideal conditions some internal abnormalities can be seen, such as absent or cystic kidneys.

Amniocentesis is a procedure where a small sample of the fluid surrounding the fetus is removed and sampled. It is a minor procedure where usually a long needle is inserted into the abdomen of the mother, and the mother is usually given local anesthesia beforehand. Only about 20-30 cc's of fluid is needed for genetic testing, and since the fluid contains cells of fetal origin, tests can be performed on the fluid to find any and all genetic disorders known.

Another procedure is chorionic villus sampling (CVS). It involves removal of villi from the chorion frondosum (small amount of tissue from the fetally derived supporting tissue). The tissue comes from cells that will develop into the placenta, as it performed early in the pregnancy. There are two methods of penetrating the womb, one similar to the procedure in amniocentesis, and the other by inserting a thin tube through the cervix. There is a higher risk to mother and fetus from CVS, and it does not detect neural tube defects. The advantage, and sole reason that CVS's are performed is that they can be done earlier in the pregnancy than most other procedures, and the tests can be performed faster without results returned sooner than other tests. This is a distinct advantage if a termination of pregnancy is necessary, because it is still a minor procedure before the 12th week.

All the benefits of prenatal screening, gone through in earlier sections far outweigh the slight risks involved in the actual testing procedures. The argument used by opponents of prenatal screening that it puts an unnecessary risk on the mother and fetus is simply very weak. The benefits far outweigh the risk, and if people wish not to have screening performed it should be for other reasons other than that they are afraid of the risks involved in the process of getting screened.

Pro - Human Cloning

Human cloning has a similarity to prenatal screening, in that there are many morals issues regarding its position now and its possible future. There have been many advances recently with human cloning, particularly in Korea where they have cloned a human embryo. They state that they are not trying to do reproductive cloning by cloning the embryos; they are doing it obtain stem cells to advance in the treatment of certain diseases. This advancement, while extraordinary, is only the beginning of what the scientists are planning on accomplishing. They state *"stem cells can be manipulated by scientists to develop into many other human cells."*[68] With this advance being on the horizon scientists feel that cures for many crippling diseases may also be looming.

> *"It is in this context of scientific and cultural evolution , coupled with the traditional medical philosophy to minimize the frequency and severity of disease, that the effective control of certain inherited disorders of man becomes a realistic and current consideration."*[69]

As times have changed, people's views also change. In this case, there have been so many advances in technology that it seems like if we did not use the technology to our

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[68] http://www.cnn.com/2004/HEALTH/02/12/science.clone/
[69] ibid

advantage and focus some time and energy on preventing the occurrences of diseases, we are taking a step backwards. Such is the case with the Korean scientists successfully cloning an embryo from which to obtain a stem cell.

Many people feel that human cloning is unethical because they feel that the clone would simply be a copy of the individual and not have individuality. This is not the case, however. The clone would really be in effect an identical twin that was born much later. No one can argue that a twin is not an individual, and hence cannot make a particularly strong argument that a clone is not an individual. If one is to believe that a clone is solely a copy of the individual, they are embracing the belief that humans' genes determine everything about their lives, when we all know this is not true. The fears that people have regarding cloning running rampant should be put at ease with the fact that genetic determinism is not what really happens, and that any clones produced would be mentally different from each other. Cloning is also a bioethical issue, just as is prenatal screening. In the future, if cloning is available, scientists may be able to tweak genes in such a way as to diminish the occurrences of genetic diseases. Many of the advances that can be made with the cloning of humans, can help to cure genetics diseases and this is particularly pertinent to prenatal screening in that scientists with the use of prenatal screening may put to action the advances in curing diseases from cloning.

In the tests done by the Korean scientists cloned human embryo's to obtain stems cells for the treatment of certain diseases as was stated earlier. Stem cells are used in gene therapy, and gene therapy is applied to patients who have genetics diseases, obviously. Gene therapy relates to prenatal screening, this is because prenatal screening's purpose is to detect problems within the fetus. Many times genetic diseases can be found if the mother has this procedure done, hence because prenatal screening has detected a genetic disease, gene therapy is an option. So because human cloning thus far is solely for the cloning of embryo's to get stem cells, and prenatal screening detects diseases that stem cells are able to treat, prenatal screening and human cloning seem to be working in the same direction. Therefore they are related in that if we would like to find cures for diseases, we should allow research to continue in the fields of prenatal screening and human cloning.

Genetic Testing: Positives vs. Negatives

In recent years there have been many advances in the approach to control human genetic disease. At this point technology has not developed so much that we are able to cure these genetic diseases, but no one can exactly say what the future holds and there are many scientists who feel that these stem cell projects are opening the doorway to actually correcting these genetic problems safely. If they are able to find a cure with this research, it will lead to a heightened sense of optimism for finding cures to all sorts of diseases that would essentially be improving the quality of life. On the other hand, therapy for these diseases can be done effectively presently and is a very realistic option. When therapy is a possibility and effects from the genetic disease can be eliminated or diminished, people should view genetic testing as a positive technology.

There are two different types of screening, one is screening for diseases and the purpose of this is to control a disease, treating it or normalizing the affected humans phenotype. The other types of screening is called carrier screening. The main way that carrier screening is used to control disease is by controlling the reproduction of the affected individuals.[70] In carrier screening the main point is the avoidance of passing affected genes from generation to generation.

As far as the future goes for genetic and prenatal screening there is one main factor that will either hinder or push along the progress; this factor is the number of facilities that can offer these tests. If the numbers of facilities rise, then the chance of the scientists finding a cure for diseases will greatly increase. This is because with more facilities comes more scientists and with more scientists, there will be more research. If the amount of research for cures increases, then the probability of finding cures tends to increase. Although public opinion regarding tests will be taken into account, it is ultimately up to the scientists and the people who hold the power regarding the creation of more facilities to decide. With recent studies and research we have found that the scientists have made many advancements. These advances may lead to a promising future where we may find cures and be able to avoid a lot of emotional distress that comes with being affected by any number of these diseases.

There are many points that must be considered in order for prenatal genetic testing to be justified. Some of the more important points listed stated that disorders that are screened for should pose a large health problem, there should be a recognizable benefit from the testing, attention to moral and ethical values should be mandatory, the tests they perform for carriers should be safe, reproducible, and inexpensive, and most importantly, accurate. Those points are just a few of many critical issues that must be considered seriously before prenatal screening is to be done. After considering all points there should be a follow up with the patients to see whether or not the testing was something that they considered to be a valuable part of childbirth for them. After all of

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[70] Milunsky, Aubrey. The Prevention of Genetic Disease and Mental Retardation. Philadelphia. 1975. 91.

this has occurred we can justify the safety of prenatal screening and how patients as a whole feel about it post-childbirth.[71]

Screening for genetic diseases has been growing because we have made so many discoveries regarding the amount of defective genes that can be found in the body. Of course as long as we find more problems in the body, we are going to have scientists who are going to research finding ways to avoid having such problems. The tests that they have been performing now are in many cases for rare diseases. In the future these tests could be used to help companies decide whom they should hire. It would not be intelligent for a company to hire someone who has a high risk for something such as a heart attack to have a high stress job.[72] These tests could be performed on the newborn children but in reality they are performed on the unborn children. Many women who bear a child who has a certain disease shows a high risk for the other child to be afflicted as well. *"For these women and their husbands, the precision of the new prenatal genetic tests has been of immeasurable relief."*[73] These tests have given families a chance to find out if the next child that they will have will be affected by the test. In the case that the baby will not be affected, they can bear the child with confidence that by bearing the child, they are not bringing about a baby who will live a challenged life regardless of the technologies that are offered. Many people avoid having these tests done because they have a moral objection to having an abortion and in many cases the sole way to fix the problem of having a baby with these afflictions is to abort the child. There are many limitations put on prenatal testing. One is that poor woman do not often have the ability to get tested as they lack the resources to pay for testing or even lack insurance. Genetic

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[71] ibid. 14

[72] Bishop, Jerry E. and Waldholz, Michael. <u>Genome</u>. New York. 1990 19

[73] ibid. 19.

testing in some cases leads to therapeutic abortion. Poor people cannot pay for testing or abortion and therefore have very limited capability to get screened for genetic disease. Insurance companies will not invest in poor people very often unless the persons requesting testing are at high risk to be a carrier of the disease. This is one other crucial limitation on prenatal screening. In essence when it comes down to the real limitation on prenatal screening, the common denominator is money.[74]

In vitro fertilization is the scientific term for forming a test tube baby. There is a test for genetic diseases that can be used in relation to in vitro fertilization, and it is called preimplantation. This test is called preimplantation because it tests the genes of the mother for genetic disease before it is implanted into the mother. This is because each "pre-embryo" has its own genetic makeup and will have distinctive genes so a mother who may be a carrier of a disease and pass it on to her offspring could use in vitro fertilization to test for genetic diseases. This is because if one of the pre-embryos has the gene, that does not mean all of them will have it, and therefore, they can individually test each one of the pre-embryo's in order to find one that will not be an affected child when it is born and therefore reduce a lot of stress on the parts of the potential parents.[75] In preimplantation each embryo is tested but in the event that there is one affected by a genetic disease not all embryo's are implanted into the women, only the disease free embryos are implanted. Once the disease free embryo's are implanted into the mother she now can have confidence in being pregnant. She will be bearing a fetus that is safe from a genetic disease even though she is, in actuality, a carrier for whatever disease she may carry. Many people find this type of testing unethical because it determines which

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[74] ibid. 309

[75] ibid. 310-311

genes are going to be used before the mother is even pregnant. They feel that this is predetermining the fate of the baby and not letting nature run its course. However, the fact remains that preimplantation can pick out the genes that are carriers of a disease and not give them a chance to infect the baby. Therefore the only thing that is being determined through preimplantation is that the baby will have a much more minute chance of being affected by a genetic disease. The determination that a fetus will have a small chance of being a genetic disease is a good thing that should not be shunned upon. The fact that this testing uses in vitro fertilization, makes it less popular than many of the other types of tests, but because they can test for certain diseases, and not use the genes that are carriers of one of those diseases, this is a very effective diagnosis and in many cases can save a family from having to abort their child and live a completely healthy life.[76] This type of testing is much less popular due to the way in which the woman is impregnated. The reason that this is a good type of testing is because it is most commonly used for women who already know that they are a carrier for the disease because that is the safest way for her to have a baby not be affected as well.

As women get older, it is more and more beneficial for them to be screened upon their pregnancy because chromosomal abnormalities are greater. The age at which most women can have the option to have a prenatal diagnosis is 35. In the event that a woman decides she is going to have a baby after the age of 35, it is in her best interest to have this procedure take place, not for her health but for the sake of her unborn child. I know that if I were in a situation where the baby that my wife was going to give birth to would have a high risk for a genetic disorder, I would highly recommend to her that we have this procedure done. This is because I feel that if my baby has a heightened chance for a

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[76] http://www.givf.com/pgt_sepv.cfm

genetic disorder, I would do all the research possible to prove to my wife that we should take the small risk to be screened and be reassured about the birth. Regardless of my input, the final choice comes down to the woman, but I would try to give her all the information necessary to feel safe enough that she is willing to undergo such a test. It is unfair to the baby to put them at a high risk because one chooses to have a baby at an older age, and it is their obligation to make sure that the baby will be safe and have no problem and in the event that the baby will have a disease, we could then take all of the precautions or make the right decision with counseling by our doctor. Because women over the age of 35 are at a higher risk of giving birth to a child with a genetic disease, prenatal screening is a should be a serious consideration upon the realization of the pregnancy.

If a person feels uneasy regarding going to have these tests done, they should talk to their primary doctor and possibly get a referral to see a geneticist. This is the person who will be answering all questions one may have regarding these procedures. As in any situation where there is a cause for concern, everyone reacts differently and the doctor who each person deals with will go to a personal level to advise his or her patients to the best option that they have to do for their family. When a family finds out that a baby they may have could be affected with a genetic disease. They have many options; they can take the risk and have the baby and deal with the possibility, they could have an abortion. In the event that they have already had a baby, and the baby was affected, they could adopt another baby. They also have the options of not having any other kids and in this case they are still perfectly able to live a happy life together.[77]

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[77] ibid. 74-75.

Many people feel that testing fetuses and trying to clone cells is taking destiny of the human race into their hands and this is a serious problem to them. However things like this have been happening in nature forever. For example the changes that have occurred in all living organisms from a single celled organism to all types of different multi-celled organisms that are in addition to humans shows that changes have already taken place and it is pretty much something that is inevitable. It is a natural thing to have happening at this point in time. The fact that things like this have occurred in nature shows that we should be able to expect changes with nature and when there are changes in nature, there are changes in human nature. This is because as we all know, when there is adversity it is human nature to try to overcome it, such is the case with trying to cure diseases. Because there are genetic diseases human nature is to cure them and by avoiding doing so, I feel like it would take more time and energy to stop prenatal screening along with so many other genetic studies that there is no real reason to try and evade it; this is because as people change and evolve they acquire new aspirations and as we live in a free willed democracy, stopping research that can help the human race is, in my opinion a step backwards.

In some cases genetic testing is used to take a general population as a whole and determine how many of the people tested would be carriers for a certain disease. Many people have a fear of having genetic tests done. This is because in most school systems, biology is not even always a requirement and when it is, there is not an extremely extensive part of the book that is dedicated to human genetics.[78] If this was not the case, many more people would have been educated about genetics and there would not be so

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[78] Tamah. Sadik. L. and Siegfried. Pueschel. M., ed. Genetic Diseases and Developmental Disorders. Boulder Colorado.1979. 26-27.

much of a fear regarding genetic screening. At the current time, many people are scared that this is taking nature into our own hand, when the actual fact is that many people need this to be done for their own reassurance, and it is much safer than what would be expected of genetic tests but many people do not realize this due to their lack of education in this field.

There are many young people in the western world who feel like genetic testing is important and something that must be done; they do not, however, believe that they could be carriers of these certain genetic diseases. *"The concept of prevalent heterozygosity with risk is unfamiliar to the majority of students."*[79] In this case we can see that many young people who are being educated now have a very low level of information regarding genetic screening. This leads us to believe that if people who are being taught things now do not understand the nature of their genetics, then their parents certainly will not be fully aware of this either. This is because technology has made so many advancements and young people are not being educated properly so they were probably educated even more poorly in the older generations.

The advantages out weigh the disadvantages of prenatal screening. In many cases prenatal screening allows for parents to have a baby when they normally would be fearful of having one. There are many women who have amniocentesis performed on them and they feel that it made them feel safe to continue their pregnancy and said that if they were not allowed to have this procedure done, they would have terminated the pregnancy due to a lack of reassurance that the baby would be safe.[80] In tests that have been conducted regarding the safety of amniocentesis, it was found that there was no distinguishable

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[79] ibid. 27

[80] ibid. 65-66.

difference in the fetal status of mothers who were tested as opposed to those who had not been tested. This fetal status refers to the occurrences of perinatal deaths in fetuses that were exposed to prenatal screening as opposed to those fetuses that were not involved with prenatal screening. Because of this study one is lead to believe that in the event that a mother is a high risk factor for carrying a genetic disease, there is no reason why she should not have this test performed on the fetus.[81] The main disadvantage has nothing to do with the safety of the baby or the mother; it is in the fact that there are sometimes false results that say there is a disorder when in reality there isn't. This fact alone deters certain types of religious families from undergoing such a procedure.

Pro - Prenatal Screening

When considering the use pf prenatal screening and it is a regular pregnancy these are the visits that one can expect to have. Of course in the event that there are implications more visits can easily be made.

First Visit	**Blood tests:** To check the woman's blood group and sometimes, to check for presence of hepatitis B virus, which might be transmitted to the baby.
	Cervical smear test: To test for an early cancer of the cervix (if a test has not been performed recently). Also called a Pap smear.
First Visit and Throughout the Pregnancy	**Blood tests:** To check for anemia in the woman, and in women with Rh-negative blood groups, to look for the presence of Rhesus antibodies.

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[81] ibid. 69

	Urine test: To check for proteinuria, which could indicate a urinary tract infection or preeclampsia.
	Blood and urine test: To check for diabetes mellitus.
	Blood pressure check: To screen for hypertension, which interferes with blood supply to the placenta and is a sign of preeclampsia.
First Visit and After ANY Infection	**Blood tests:** To screen for rubella, which can cause defects in the baby, and for syphilis and HIV (the AIDS virus) which can also be passed on.
First 12 Weeks	**Chorionic villus sampling:** May be performed if there is a risk of certain genetic (inherited) disorders being passed on.
16 to 18 Weeks	**Ultrasound scanning:** Is carried out to date the pregnancy accurately and to detect any abnormalities present in the fetus.
	Amniocentesis: Carried out on older women and those with spina bifida or Down's syndrome to detect possible abnormalities in the fetus.
	Blood test: In some cases, the amount of alpha-fetoprotein in the blood is tested to determine whether the baby has spina bifida.
	Fetoscopy and fetal blood sampling: In some cases, these are carried out if there is doubt about the normality of the baby.
High-risk or overdue pregnancies	**Blood and urine tests:** To assess placental function and fetus health.
	Electronic fetal monitoring: To check on the fetal heart beat.
	Ultrasound scanning: Extra scans may be recommended to assess fetal growth and development, location of placenta, amount of amniotic fluid.

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This chart shows that in the event that a pregnant woman decides to undergo prenatal screening, she will be given extremely serious treatment and will be provided

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[82] http://archives.obs-us.com/obs/english/books/pg/pg230.htm

with multiple doctor's visits. The woman will be monitored during pregnancy and it appears they go through many precautions to adhere to safety requirements.

When one is considering the use of prenatal screening, it is important to know the facts before going through such a process. There are certain techniques applied when performing these prenatal testing. These techniques may be invasive or noninvasive. In the event that someone is against prenatal screening, they may be missing out on information regarding the pregnancy that could be detrimental to the baby or the mother. In prenatal diagnostic testing, the mother and father to be can be helped along the way by knowing exactly where they are and can more easily manage the remaining time before the baby is born.

In the event that a complication is found to be too dangerous for either the parents or the unborn baby, the parents, along with the help of their doctor, can decide whether it is safe to continue with the pregnancy. Although abortion seems to be a ghastly craze are times that the baby is going to affected with a disease that will kill the baby and it is unavoidable, at this time abortion seems to be the only optional. One other serious factor that is often neglected with regards to prenatal screening is that it can help doctors use particular information that has been found to work on minimizing such complications with families in similar situations in the past. Prenatal screening is a helpful tool for doctors. If prenatal screening is continued in the future and continues to improve, there is a chance that the occurrences of perinatal deaths will drop drastically, not because of the screening but because of the fact that continuing research and allowing prenatal screening to carry on can only help researchers to find out more concerning these diseases and the specific characteristics of the diseases. Because of this, researchers may possibly find ways to treat carriers before they are impregnated and avert future occurrences of genetic diseases. Once again we are showing that prenatal screening should continue. Prenatal screening gives the doctors and researchers the chance to see multiple occurrences of a disease and then possibly find a way to avoid the transfer in as safe a way as possible. There is a lack of confidence in prenatal diagnosis but if we ignore and do not embrace the research for prenatal screening it is more or less as if we are settling to have many babies be left with disease and have totally ill-prepared parents. These parents will most likely be shocked because they were unaware of the possibility of having a diseased baby. In this case the shocked parents have a much smaller chance of knowing where treatment is available, they may not have saved enough money for treatment and even may not have insurance to cover any types of treatment. If testing continues these parents could have avoided much hassle by preparing all necessary treatments in advance. Babies with diseases can still be born but more effectively treated as compared to babies who were not screened solely because of the fact that the parents were well-prepared. If we are willing to allow for more and more research then we are also going to help further the research for curing genetic diseases. It is our obligation to work for the safety of each generation to come. Ignoring advances in technology that can decrease risks of genetic diseases is immoral in my opinion because the safety of our children and their children can be put at a higher risk.

There is a low chance of miscarriage when amniocentesis is performed, usually only one out of every four hundred births miscarriage. Amniocentesis is performed sort of late into the pregnancy, when the patients want to find out the results earlier in their pregnancy. One option would be performing a test called, chorionic villi sampling. This particular test can show the status of the fetus earlier into the pregnancy with a 1-2% chance of miscarriage. Because the chances of miscarriage with these types of prenatal screening are not high, I see this as a safe technique. It is a personal choice for each individual family, but safety of the baby from the test is not a huge factor and should not be a negative aspect in the decision making process for the family. [83]

Because of advances in prenatal testing, it is now possible for women who are under the age of 35 to see if they are at a high risk for prenatal abnormalities. In the event that they are found to have a high risk for prenatal abnormalities, they are then able to request further testing, whereas in the past, it was virtually only women who were over the age of 35 to be tested in these ways. There have also been many advances in the recent past that can be very beneficial in finding out whether or not the women is a carrier of certain genetic diseases, and can cause the fetus to be a carrier of these particular diseases. The DNA tests are now able to identify such diseases as, cystic fibrosis, fragile X, Tay Sachs, Gaucher, Huntington and other diseases.[84]

There is one very important reason that prenatal screening should be seriously considered and not disregarded as a bad thing. This is because the test is not for the parents, but it is for the baby. It is clear that prenatal screening is important because in the event that there is a problem in the unborn fetus, the doctors will have a specialist in the delivery room who will be sure that the baby is going to be as well taken care of as possible. One important factor that also should not be neglected is that these tests may come out wrong sometimes and give out a positive result when there was really no

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[83] http://www.sacbee.com/content/women/reproduction/story/6378628p-7331407c.html

[84] http://www.givf.com/decadev.cfm

problem.[85] But the risk of the fetus being negatively affected by the screening is very low, and because sometimes screening can prove to be a factor in saving a baby's life, a mother who is at risk of being a carrier for a genetic disease should not see the possibility of a false test as a deterrent. Even though a false positive is a bad thing to have happen, more often than not this will not cause a problem and I am 100% sure that there are more babies who are saved because the parents knew about a disease as opposed to the amount of times there were false positives. If one is to put herself into a situation in which they had the opportunity to run these tests, and declined, I am quite sure that they would have a great deal of regret in the event that the baby is born with one of the genetic diseases that can be detected by prenatal screening. As a result, the fact that a baby would most likely be unharmed and even possibly saved for the reason that the proper precautions were taken before the birth because of prenatal tests, shows that the benefits outweigh the negatives, with the exception of a false positive diagnosis. The baby could in essence be saved by prenatal screening because it allows for a specialist to be present if needed and treated more quickly for the disease than compared to if there was no prenatal testing done.

Economically prenatal screening seems to be much more economical than many people had once thought.

> *"Perinatal transmission of hepatitis B virus (HBV) from an infected mother to her infant occurs at a high rate, but immunization of infants at risk has been shown to reduce the transmission rate to 5 to 10 percent. Investigators evaluated the cost-effectiveness and potential impact of routine screening of pregnant women, with subsequent immunization of newborns at risk.*
>
> *The findings suggest that routine screening in the U. S. would result in an annual net savings of more than $105 million, and that up to 1400 cases of*

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[85] http://www.babycenter.com/dilemma/pregnancy/prenatalhealth/1135775.html

> *chronic liver disease would be prevented for every 100,000 women screened. An accompanying editorial concludes that universal screening for hepatitis B surface antigen is warranted by the available data."* --*THL*[86]

This statement was made in 1988. At this time many people felt that prenatal testing was not economical. This statement proves the assumption that many made to be false. As one can plainly see that prenatal screening is seemingly very important. Because of findings that researchers establish in 1988 they ascertain prenatal screening to be cost effective in that it will annually save over 100 million dollars which would certainly put some relief on the national debt. Not only does prenatal screening seem to be very cost effective, these results found by the researchers shows that prenatal screening will also be estimated to save upwards of 1000 people per year from becoming infected with a genetic disease.

One serious thing that people have to understand with regards to risks is that depending on each individuals perception of the particular risks directly relates to how he or she approaches that risk and some people are much more anxious than others. So this shows that as this is a moral issue and there are risks involved, the choice on whether or not to conduct prenatal tests will change depending on the individual regardless of information they have been given because of their perception of risk.[87] Pessimistic people for example would not take as much of a risk as optimist. The optimist looks at the screening as a way to help him or her and the pessimist feels that the screening will produce a false positive and do nothing but put unwarranted stress on the pregnancy. Most people in the population are somewhere in the middle of the pessimist and the optimists. Because most are in the middle and can be swayed either way depending on

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[86] http://general-medicine.jwatch.org/cgi/content/full/1988/122/1

[87] http://strategis.ic.gc.ca/epic/internet/inbac-bec.nsf/vwGeneratedInterE/bk00131e.html

the facts on whether or not they feel like prenatal screening is a good or bad thing. As we saw previously the facts show that overall prenatal screening is beneficial. As a moral issue if something is safe, effective and for a good cause, it should be embraced. Consequently we can show that in the end the facts will prevail and prenatal screening will end up being a standard in crucial situations.

For advocates of prenatal screening, neglecting to perform such tests is in fact neglecting their baby in the event they are passing traits that carry diseases to the baby. The screens could have possibly detected such problems within the fetus and given the future parents the proper insight as to how they should approach childbirth, whether that be treatment upon birth and follow up treatment or therapeutic abortion. Advocates feel as if people who have a moral issue with prenatal screening are mostly ignoring the facts or just under-educated about the facts of prenatal screening. Supporters of prenatal screening believe that with an open mind, others should be able to see that prenatal screening is a breakthrough that can save lives!

Con Argument

Over the past 3 decades prenatal screening has become more and more popular with pregnant women. It has gotten to a point where almost every pregnant woman is getting screened. However, the only information these women know are the advantages of the screening procedure. Not many know about all its disadvantages. It seems society only wants to think of prenatal screening as a good thing; when in actuality it is not as good as people are lead to believe. There are many flaws in this procedure that people, especially pregnant women, should know about. Such as the risks of "false positives", miscarriages, abortions, and a pre-exiting conditions. Each one of these risks is enough to stop a screening from happening. Prenatal screenings costs thousands of dollars to go through, why spend that money when you are putting a greater risk on yourself? Once people know the facts about prenatal screening they will understand why it should not be performed.

Amniocentesis / Malpractice

Amniocentesis is screening procedure many pregnant women receive. The recommended age for this test is 35 years or older. The reason for this is women 35 years and older are more likely to have a child born with a defect, than compared to patients under 35.[88] If patients under 35 years of age should not be receiving this test, then why are they? The reason for this is to prevent the patient from suing. Doctors order these test to make sure they did everything they could to determine if the fetus is abnormal. If

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[88] Unknown Author. "MedicineNet.com" Amniocentesis. <http://www.medicinenet.com/Amniocentesis/article.htm> 4 January 2004.

doctors do not perform some tests on a patient and the birth of an unhealthy baby occurs, then the patient could possibly sue for malpractice. Therefore, patients are being given amniocentesis when they are not recommended to. What patients do not know about amniocentesis is that it has a serious risk. Patients who receive this test are more likely to have a miscarriage. For every 200 patients that receive this test, 1 will have a miscarriage.[89] Amniocentesis could kill your child.

In France prenatal doctors are facing a huge crisis. Their insurance rates are soaring, due to the possibility of being sued for malpractice, while the government fixed-fees are to low. Doctors are being forced to overload with patients and work long tiresome hours just to make decent revenue. In France ultra sound only costs around $35 in small towns, and $80 in Paris; while giving birth costs a mere $157, including a few days in the hospital. "I delivered 120 babies last year, but at this rate I can't make money anymore," said Michael Serfaty, 43, an obstetrician in the southern city of Aix-en-Provence. "We work weekends and nights. It's a crazy life."[90] Doctors are threatening to quit their jobs if nothing is done. The money is not worth the amount of work they are doing. “Our organization gets letters every day from doctors saying they are giving up,” says Bessis, who heads France's College of Echography, a membership organization for 200 senior specialists in the field.” Bessis fears that the country is going to lose a lot of its prenatal doctors, and there will not be enough to test the expected 800,000 unborn children a year in France. As a result more babies will be born with some type of defect.

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[89] Unknown Author. “Peace Health”, Should I have Amniocentesis?
< http://www.peacehealth.org/kbase/dp/topic/aa103080/dp.htm> 20 January 2004.

[90] Vivienne Walt. USA Today “French legal fears hamper prenatal screening”. Copyright 2002, USA Today, a division of Gannett Co., Inc. 4/9/2002

False Positives

Amniocentesis is not a common test to be done on the first day of testing. It is usually done if another test has come back with a high chance of a defect in the fetus. This, however, happens more than one may believe. The results for screening tests sometimes come back with a positive result, when in actuality nothing it wrong. These results are called “false positives”[91]. Dr. Jacob Canick of the AFP lab at Women and Infants Hospital of Rhode Island says, "It (Enhanced testing) cannot tell you with certainty that you do or do not have an affected fetus."[92] Patients need to realize if they receive a positive result, it does not mean with certainty that they will give birth to a problem child. “False positives” happen often and lead to more tests, such as amniocentesis. Prenatal screening results are scary, because even if you do get a negative result it does not mean you are definitely going to give birth to a healthy child. No screening test is 100% accurate. Every type of prenatal test has its flaws.

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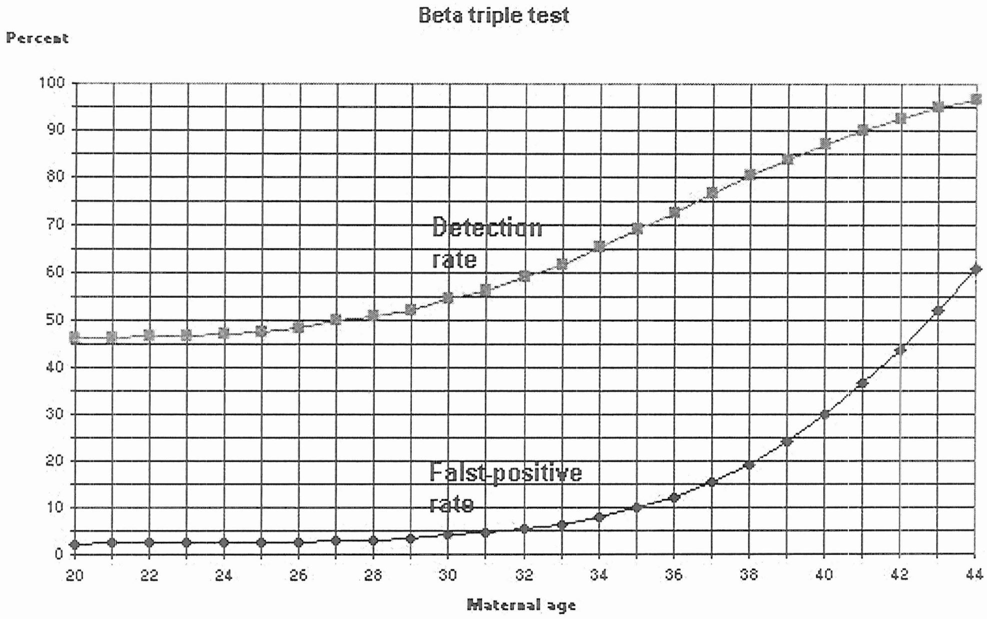
[91] Jennifer J. Buescher. “Journal of Family Practice” False-positive mammograms increase follow-up rates. (Patient Oriented Evidence That Matters: practice recommendations from key studies). <http://www.findarticles.com/cf_dls/m0689/7_52/106026454/p1/article.jhtml> 1 February 2004.

[92] Tamar Weiss. “Pregnancy Today”, Prenatal Screening: The Pros and Cons of AFP. < http://pregnancytoday.com/reference/articles/enhancedafp.htm> 23 September 2003.



[93]

The chart above shows information from one of the most popular Down syndrome screening tests, the beta triple test. The information shows the detection rate and the false positive rate according to age. As the chart shows, the false positive rate greatly increases with age. Patients between 20 and 28 have about 4% chance of a false positive. Even though this percent is low, there is still a possibility of receiving one. However, the detection rate for patients within these ages is only 48%! This means only about half the affected fetus' get detected. This means if you should receive a negative result, you cannot completely believe it. As age increases, so does the detection rate; however, the false positive rates do as well. At the age of 40 the detection rate is about 87%. This is a lot better than the detection rate between 20 and 28. Although, the false positive rate increased to 30%! This means a lot of false positive are given to people with a healthy

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[93] Unknown Author. "LEEDS ANTENATAL SCREENING SERVICE" Beta Triple Test. <http://www.leeds.ac.uk/lass/beta_triple_test.htm> 22February 2004.

fetus. Whether you get a negative or positive result you cannot believe it 100%, which raises concerns whether the tests should be performed at all considering that there is a chance they could be wrong.

AFP (alpha-fetoprotein) is a very common screening procedure. It is done by taking a blood from the mother's bloodstream and measuring the level of AFP produced by the fetus. However, it is not very accurate. 5% of all women screened receive abnormally high readings. Of the 5% only 1 or 2% actually have a abnormal fetus. Therefore, if 2000 patients were tested about 100 will receive abnormal readings, and only 1 or 2 will have a fetus that has a defect. Receiving a false positive is not the only problem with the AFP test. The AFP test also misses 40% of spina bifida cases, 10 % of anencephaly cases, and 80 % of fetuses with Down syndrome. All of which return a negative result. [94]

Fetus Rights

False positives happen all the time, but what are you going to do if you receive a positive result? You will not know if it is a "false positive" or if it is true. People who receive a positive result go on to other tests, and if still positive they have a choice whether to continue the pregnancy or abort it. This decision is unjust to the unborn fetus. The fetus is a living human being, and should have all the rights that come with it. Many religions such as the Christians, Mormons, and Anglican believe in this. The Christians stated,

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[94] Helen Klein Ross. Mothering, "The hazards of AFP prenatal testing. (alpha-fetoprotein)". COPYRIGHT 1990 Mothering Magazine, 6/22/1990

> *"Even though a United States Supreme Court decision legalized abortion in 1973, abortion is still immoral and sinful. This stand is founded on the biblical truth that all human life is created in the image of God (Genesis 1:27). From that truth issues the long-standing Christian view that aborting the life of a developing child is evil."*[95]

The Mormons had a similar opinion, but with a few exceptions,

> *"The Church opposes abortion and counsels its members not to submit to or perform an abortion except in the rare cases where, in the opinion of competent medical counsel, the life or good health of the mother is seriously endangered or where the pregnancy was caused by rape and produces serious emotional trauma in the mother. Even then it should be done only after counseling with the local presiding priesthood authority and after receiving divine confirmation through prayer."*[15]

The Anglican religion also stated their side when the said,

> *"All human life is sacred from its inception until death. The Church takes seriously its obligation to help form the consciences of its members concerning this sacredness....We regard all abortion as having a tragic dimension, calling for the concern and compassion of the community."*[5]

These religions feel strongly on this issue, but as only portion of the population is actually religious ethical issues raised by religious ethicists don't concern many people. However, people are still getting abortions. The U.S government declared fetus' not to be human in the case Roe v. Wade (1973), and therefore abortions were legalized[96]. Some people agree with the belief that the fetus is not a human until its first breath of air, and therefore women's rights outweigh the fetuses. This means the future of the fetus is what the women wants it to be. This is unjust; how can the fetus be declared not a human? The human fetus has a heart (after only 5weeks), it own blood type (after 7 weeks), a brain

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[95] Author Unknown. "Religious Tolorence.org" Statements about abortion access by religious & other groups, < http://www.religioustolerance.org/abo_chur.htm> "22 Novemeber 2003".

[96] "RoevWade.org. Supreme Court Case. <http://www.roevwade.org/court.html> 7 October 2003

(after 12 weeks), and also has facial features, hands, fingers, and much more(after 7 weekes)[97]. This is a living human inside the female body and should be treated as one. Pro-Life activists support this belief and state,

> *"Medical, biologic and natural science has long since proven that this is a living human from conception. Our founding fathers, in the charter of this republic spoke clearly, stating "we hold these truths to be self evident, that all men are created equal and that they are endowed by their Creator with certain unalienable rights — of life, liberty and the pursuit of happiness."*[98]

This declares life to begin during conception; when the male sperms merge with the female's egg, causing fertilization. During this stage the zygote the fertilized egg has 46 chromosomes, which is enough to create human life.[99] The fetus is a developing human child, and killing it should be against the law as murder of any human is against the law.

15 states in America have recently decided to make their own laws about the fetus. These 15 states decide to give rights to unborn children / the fetus. With these laws being made, the unborn child is protected from harm,[100] and anything that could potentially harm the fetus is considered a crime. The laws against murder in some of these states declare:

> *"**Idaho:** Murder is defined as the killing of a "human embryo or fetus" under certain conditions. The law provides that manslaughter includes the unlawful killing of a human embryo or fetus without malice. The law provides that a person commits aggravated battery when, in committing battery upon the person of a pregnant female, that person causes great bodily harm, permanent disability or permanent*

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[97] Unknown Author. "Westside Pregnancy Resource Center" Fetal Development. <http://www.w-cpc.org/fetal1.html> 20 January 2004.

[98] Dr. J.C. Willke. "AbortionFacts.com" Why Can't We Love Them Both, <http://www.abortionfacts.com/online_books/love_them_both/why_cant_we_love_them_both_3.asp#Religious%20Belief%20vs.%20Civil%20Rights> "6 January 2004".

[99] Dianne N. Irving. "International Journal of Sociology and Social Policy" When Do Human beings begin? < http://www.abortiontv.com/WhenDoHumanBeings.htm> 7 February 2004.

[100] "National Right To Live", State Homicide Laws That Recognize Unborn Victims: Full-Coverage Unborn Victim States. < http://www.nrlc.org/Unborn_Victims/Statehomicidelaws092302.html> 16 February 2004.

> *disfigurement to an embryo or fetus. Idaho Sess. Law Chap. 330 (SB1344)(2002)."*
>
> ***Illinois:*** *The killing of an "unborn child" at any stage of pre-natal development is intentional homicide, voluntary manslaughter, or involuntary manslaughter or reckless homicide. Ill. Comp. Stat. ch. 720, §§5/9-1.2, 5/9-2.1, 5/9-3.2 (1993). Ill. Rev. Stat. ch. 720 § 5/12-3.1. A person commits battery of an unborn child if he intentionally or knowingly without legal justification and by any means causes bodily harm to an unborn child. Read with Ill. Rev. Stat. ch. 720 § 5/12-4.4.*
>
> **Arizona:** The killing of an "unborn child" at any stage of pre-natal development is manslaughter. Ariz. Rev. Stat. §13-1103 (A)(5) (West 1989 & Supp. 1998). Also to be read with Ariz. Rev. Stat. § 13-702(c)(10).

However, these laws do not say anything about abortion. Abortion is killing the fetus, and should be treated as manslaughter. How can punishments be given out to people who harm the fetus, but not given to the mother who chooses death for her child? An updated bill should be passed declaring all abortions illegal, and give the fetus all the rights it deserves – the same rights any human is entitled to. The rights the Constitution is in place to protect.

Murder is defined as the unlawful killing of one human by another, especially with premeditated malice[101]. This is exactly what women, who choose abortion, are doing. They are killing a human life, and do it intentionally. Some doctors are against the abortion procedure for this reason. Dr. Nathanson is one of those doctors. He believes, "*A woman has the right to go to bed with who she wants, but she can not choose death for her child. It's a direct violation of human rights.* (Koval i grid c-7)".[102] Once the child is conceived it has the rights of a human.

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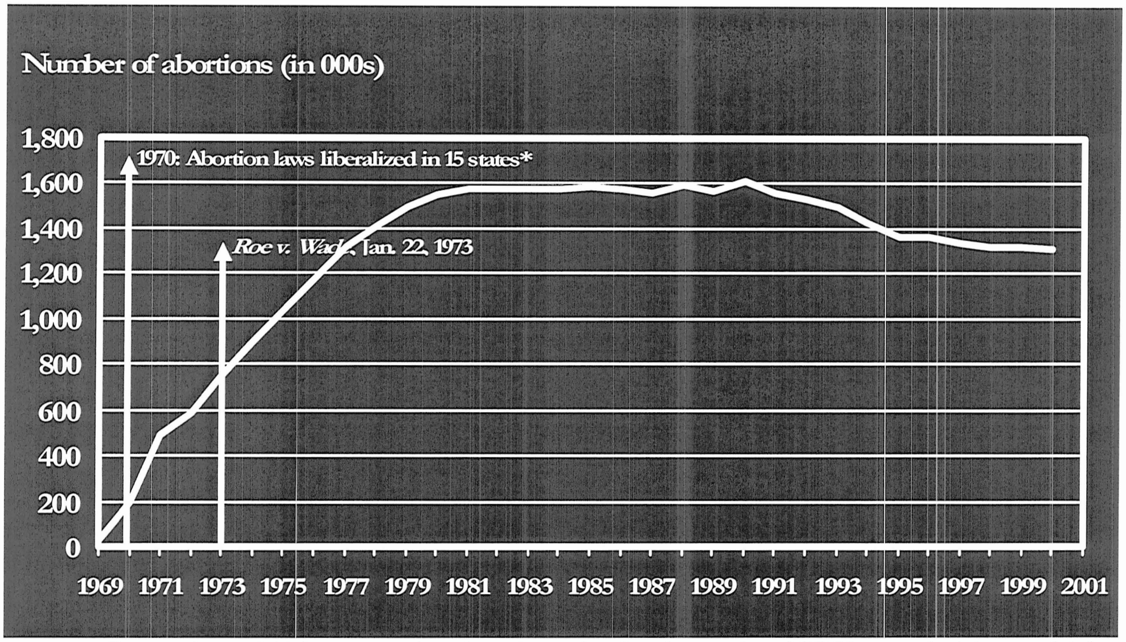
[101] "Dictionary.Com" <www.dictionary .com> 2004, Lexico Publishing Group, LLC.

[102] Author Unknown. "Study World, Abortion, <http://www.studyworld.com/newsite/ReportEssay/SocialIssues/Abortion%5CAbortion-381147.htm> 2 February 2004.

Abortions

In America, the Alan Guttmacher Institute reported 1.31 million abortions per year![103] That is over 3,500 abortions per day! Of these 1.31 million abortions the CDC, Centers for Disease Control and Prevention, declared 1.5% are done after 21 weeks of pregnancy. That is 53 late abortions per day, and almost 20,000 per year! The number of abortions grew dramatically after 1973, when the procedure was legalized in the U.S. as shown in the graph.



Screening children can be dated as far back as the 1970's, and this could be a reason for the large increase in the number of abortions. People could have been told that their child will have a disorder and choose to cancel the birthing process. Today this is a huge concern in many hospitals performing prenatal screenings. That is why if a patient is told that their offspring will have a high chance of a defect, then the hospital supplies a counselor for them to talk to.[104] These counselors cannot force the patients to continue

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[103] Unknown. "The Alan Guttmacher Institute", Abortion, < http://www.agi-usa.org/sections/abortion.html> 19 January 2004.

[104] Unknown Author. "Howard University: Center for Sickle Cell Disease", For Parents: Newborn Screening. <http://www.huhosp.org/sicklecell/parents.html> 12 December 2003.

the pregnancy, but they help them discuss other possible choices. Most of the time, however, patients choose abortion.

Genetic Counselor

By receiving a positive result, more money is likely to be spent on a genetic counselor. Even thought the hospital supplies the counselor, you may still have to pay for his/her time. Without the genetic counselor you cannot completely understand what your results mean, and what you should do. Genetic counselors will help you, but even they do not know everything. More is becoming known about genetics and in turn the technology of prenatal screening is making advances along the same road. There is still a lot unknown about genetics and new advances are being made every day. If scientists are still discovering new things about genetics that means that doctors must constantly be learning new things to keep up with the technology. Therefore, they cannot completely and accurately diagnose certain genetic disorders. People need to understand that even if you go to a genetic counselor it doesn't mean they will tell be able to give you information that is 100% accurate.

Psychological Problems

Abortions not only kill your child, but it damages the family who choose it. After an abortion families are known to suffer psychologically[105]. The parents had trouble mourning their lost one. Knowing they are the reason their child's life is over makes the

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[105] Dr. Carlson Aronson. Abortion: The Cruel and Scary Truth. <http://ed.augie.edu/~tosaboe/abortion.html> 1 February 2004.

death harder to deal with. Other problems also occur such as isolation, alienation, and fear of rejection by people who might not approve of their decision. These problems could seriously hurt the status of a marriage. Sadly, the parents are not the only one affected; their children are. If a child finds out about the abortion process, they too could suffer from it psychologically. They may feel insecure and wonder if they mess up what will happen to them. Other problems to the child are trouble sleeping, separation anxiety, anger, and school troubles.

If the birthing process is followed through and then the child dies then these psychological problems are not as severe in both the kids and parents.[12] Naming the newborn and being able to touch and see it makes the grieving process easier. Also, knowing they had no part in cutting the newborns life short helps. Therefore, there are more psychological problems associated with abortion then losing a child after birth. [12] Therefore, even if the child is found to have a terminal problem the birthing process should be followed through for the family's health.

Abnormality Rate

In America there were an estimated 4,040,000 births this year, and 122,000 of them were born with some kind of abnormality.[106] That is only 3% of all the births. That percentage is extremely low. If the odds are so low in abnormal births, why are so many people getting screened? By going through the screening process you are making yourself stressed, and worried about the health of your child. 3% is a small percentage to worry

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[106] Unknown Author. " California Birth Defects Monitoring Program", Birth Defects Facts and Figures. < http://www.cbdmp.org/pbd_facts.htm> 7 October 2003.

about, yet so many people get screened. Getting screened seems like a waste of money. Why spend thousands of dollars to find out your unborn child is in the 97 percentile of healthy babies? Parents should love their child no matter how they turn out. What if a baby is born healthy and later in life is involved in an accident, and as a result is mentally handicapped? Are you going to disassociate yourself from them? Love your child for who they are, and not who you want them to be. God created all of us for a reason, and we need to learn to accept his doings (only applies to those who believe in the existence of a God).

Pre Existing Conditions

Prenatal testing could cost you in the long run. In the future if screened and found to have a mutated fetus, health insurances may not cover your child.[107] They say if you are screened and found to have an abnormality it is a pre-existing condition, and thereby not covered. Soon most health insurance companies will require prenatal screening, and no patient's results will be private. People will have no choice but to receive an abortion. Society will just not allow abnormal babies to be brought into the world. If they are, then they will receive no special treatment and no extra money. This is because they were born by choice.

Already today some health insurance companies are denying coverage to people with a greater chance of getting sick later in life. They require a physical exam before they get accepted, and if something is wrong then they will not get covered. Even some

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[107] Stephan Rich. "Journal of Law, Medicine & Ethics" Genetic privacy laws and patients' fear of discrimination by health insurers: the view from genetic counselors. 9/22/2000.

jobs are now hiring people with better health. This way they don't need to pay as much for their health insurance rates.

The "Perfect Child"

What if abortions became illegal? Would prenatal screening be as popular as it is today? If the answer to this question is no, then there is a problem. People need to learn to love their child for whom they are. Children with a defect can still live long healthy lives. By receiving abortions when given a positive result, you are ending your child's life before it begins. In a way this is discriminating against people who are different. People would rather kill their own child if he/she was different. If this continues prenatal screening will shape the world to our wants. We'll want all our children to have 5 fingers and 5 toes, we want our children to be accepted by society, and we want our children to be "perfect". All these wants does not make screening / abortions right. From the moment the child is conceived it has the right to live, even if it doesn't meet the requirements of its own parents. Children cannot be killed for being different. With everyone being different the world it makes it a better place.

Prenatal screening could change the world if it becomes the norm. With screening being the norm, people who are born with some sort of problem will be looked down upon by society. They will be treated differently and not given equal rights. People will not only be separated by their class, but also their well being. "*Children born with defects that could have been diagnosed in utero may no longer be looked upon as "Nature's mistakes" but as parental failings.*"[108]

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[108] Rob Blezard. Who Will Weigh Genetic Tests?. <http://www.thelutheran.org/9607/page20.html> 22 February 2004.

Already in today’s society parents of a kid with Down’s syndrome are being questioned, “Didn’t you have an amniocentesis?” As each screening is being occurred society is slowly riding the world of abnormal children. Soon it will not be “Didn’t you have an amniocentesis?”, but it will be “Why did you let them live?” Society is slowly pressuring parents to give birth to a normal child; this means more abortions / deaths to abnormal ones. The world is heading for a change if prenatal screening continues to shape our children. “"*It's safe to predict that eventually we'll have 300 to 400 tests for defective genes--starting with cystic fibrosis, Huntington disease, breast cancer and Alzheimer disease--that we can do before a baby is born*," says Ted Peters, professor of systematic theology at Pacific Lutheran Seminary and Graduate Theological Union, Berkeley, California.[8]” The genetic revolution is among us today. 80% of people who receive a genetic makeup of a fetus with Down syndrome choose abortion. Soon there will be other diseases being wiped out. More and more abortions will be taking place, until the fetus is declared to be normal. At that time the world will be dominated by the “normal” humans, and abnormal ones will be slim to non existent.

A patient in her early 30’s had been found to be affected by Alzheimer's disease by 40.[109] She knows she is a carrier of the trait, and does not want to pass it to her newborn. Doctors used a procedure known as pre-implantation genetic diagnosis, or PGD, to help the women give birth to a perfectly healthy child. This child will have no worry about inheriting the disease that haunts its mother. This test was performed by extracting the patient’s mature eggs, and testing them for the deformity. After the tests were complete 6 out of the 15 eggs were found to be perfectly healthy. 4 of the 6 healthy eggs

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[109] Karen Springen. “Newsweek” Risk-Free Babies: The mother is destined for early Alzheimer's. Gene tests brought her a child who is not. What's next? 3/11/2002.

where then placed back in the women's uterus, and the perfect child was born. This story had a happy ending, yet should it have been done? In less than 10 years the women will be incapable of taking care of the child. This procedure will allow women who are diagnosed with a life threatening disease to have a perfectly healthy child. This is going to cause more children to be put up for adoption. Prenatal screening is already evolving into what people feared: genetic engineering.

Genetic Manipulation

In recent years genetic screening has made remarkable strides as a whole. Today it is possible to do things that most of us could not even imagine as little as 5-10 years ago; and this is only the beginning. The science of prenatal testing was originally designed to identify and cure severe mutations or hereditary diseases. For example, if one parent was a known carrier of a particular disease they might be advised to have their fetus tested in order to see if it also carried the disease. Another approach might be to test one or both parents who might not know their genetic makeup for mutations or diseases associated with their particular ethnic group-such as cystic fibrosis in Caucasians, sickle cell anemia in African Americans, or Tay-Sachs for Ashkenazi Jews.[110] The fetus itself might also be tested in the same way. The results from the test would not only give the parents and doctors information regarding the health of the soon-to-be baby, but it would also tell the parents if they were carrying a recessive gene disorder. While this technology is valuable, it does put parents in a compromising position. On one side there

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[110] Andrews, Lori B. Future Perfect. New York: Columbia University Press, 2001

is pressure, both self-induced as well as from friends and family, to ensure the well-being of the child. On the other side there is the fear of playing God and not letting nature take its course. Along with the difficulties placed on parents, prenatal testing also gives rise to a myriad of other ethical issues such as abortion of diseased fetuses, inaccurate testing and the fact that very little is known of the long-term effects of such testing. Despite the ethical issues surrounding prenatal screening, the majority of Americans support testing for severe or fatal diseases, but few support testing for minor disorders. Unfortunately the science of prenatal screening is branching off into two much more risky and controversial areas: human cloning and genetic manipulation. Those who oppose prenatal screening believe that it may become linked to future technologies such as genetic manipulation and human cloning. Because of the results of animal cloning experiments, with high failure rates it is the general consensus that the same results will be seen in human cloning if it were ever to become a reality. Many outside the field of genetic science, who are on the outside looking in, believe it is possible to perform prenatal genetic screening as a way to control the quality of cloned fetuses. This is only partially true however because current prenatal detection technologies will not detect the types of epigenetic disturbances that may occur with cloning.[111] As of right now there are no tools to detect some possible defects which means that the technology of prenatal screening must make advances as human cloning also makes advances. One example of this symbiotic relationship between prenatal screening and human cloning is the recent success of Korean scientists to clone human embryonic stem cells. Stem cells are important to cloning as they can be used to create organs for therapeutic cloning. They're

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[111] Why We Should Not Clone Humans.
<http://www.ama-assn.org/ama/pub/category/4560.html>

important to prenatal screening because of the possibility of preimplantation of stem cells to cure certain genetic diseases or mutations. Unfortunately there is fear that technologies of human cloning as well as prenatal screening will be abused similarly to genetic modification. Prenatal screening has given rise to the science of genetic therapy, in which the diseases or mutations discovered by prenatal screening are removed or fixed. Scientists fear that the next step will be for genetic therapy to give rise to genetic modification. With the ability to correct mutations in diseased fetuses comes the desire to manipulate the genes of those fetuses that are not mutated or diseased. "Technologies based on advances in genetics, pharmacology, neuroscience and related fields of biomedicine have the potential to help the sick and provide relief to the suffering, but they also have the potential to be used in ways that lack clear medical benefits or may even prove to be improper or unethical"[112]

The days of creating a human from scratch may still be far off, but not all that far. On June 26, 2000, with much fanfare, scientists working on the taxpayer-supported Human Genome Project announced that they had completed a working draft of a genetic blueprint for a human being. This knowledge allows scientists to know exactly where chromosomes are located on DNA. The next step in the process would be to break down each individual chromosome and identify which of the 3.2 billion chemical "letters" are located on each of the 46 strands of DNA in every human cell.[113] The Human Genome Project was set to be completed in 2005, but last year the project was completed ahead of schedule. The possibility of building "designer babies" may become a reality in the coming few years.

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[112] Staff Working Paper 7.<http://www.bioethics.gov/background/workpaper7.html>

[113] Sally Deneen, E Magazine, 2001

"Who should play God?" Not only is this the title of an insightful book written by Jeremy Rifkin in 1977 predicting the future of humanity, it is also the central question swirling around the science of genetic manipulation. Genetic manipulation has no place in our society. The obvious risks concerning the welfare of the fetus are not the only concerns. The key concern is actually the effect creating "designer babies" will have on the human race in its entirety. Manipulating a human's genetic code to display certain characteristics in their appearance or physical abilities literally takes nature out of the hands of nature. Darwin's theory of "evolution by means of natural selection" would be all but destroyed[114] if humans started fabricating other humans according to their preferences. Current technology only allows parents to choose as much as the sex of their child, but with any funding and social acceptance parents might someday be able to pick any of millions of traits for their children.

> *"Today, any couple with several thousand dollars to spare can choose the sex of their offspring, while parents who are carriers for certain genetic disorders can undergo IVF and have the resulting embryos genetically tested to ensure their children are free of disease. Tomorrow, parents may be able to enhance their offspring with designer genes. One day, the fertility industry's efforts to help couples conceive could bring society to the brink of altering the genetic heritage of the species."*[115]

The thought of creating a human to the specifications of what some selfish parent wishes their child would be leaves many people feeling uneasy. Every parent has wishes for their children, but part of being a parent is loving the child you create and raising them to be the individual you always hoped they could be. With genetic modification however, any family with enough money to spare can create the child they want from

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[114] Tudge, Colin. The Impact of the Human Gene. New York: Hill and Wang, 2000

[115] Brownlee, Shannon. Designer Babies. <http://www.washingtonmonthly.com/features/2001/0203.brownlee.html>

scratch and not have to worry about how the child will turn out. Of course the idea of picking designer genes is only theoretical as the expression of individual genes is determined at random. "Once if became acceptable to engineer a single gene, then why not two? If two, then why not twenty, or two hundred?"[116] The science could go so far as parents sitting around in a doctor's office browsing through a magazine and circling or checking off traits they want their child to have. Whether it be the brains of Albert Einstein or the athletic ability of Michael Jordan parents could say "this is the baby I want you to create for me" then pull out their checkbook or visa card.

The next question about creating "designer babies" would be: does it work? Whether bioengineering "designer babies" will actually work is a matter still unknown. Genetic treatments and tests have been coming about so quickly that physicians don't have enough knowledge of them assess their worth. Individuals rely on their physicians for their medical expertise when it comes to receiving the best treatment possible, but the serious lack of knowledge when it comes to genetic treatments makes it impossible for doctors to relay any type of useful advice. As of today genetic manipulation does not work because there is still so much to be learned. The only true way to know if genetic manipulation will work is by human experimentation. Presently all we have to say whether the process will actually work is information derived from animal experimentation. For example: in the year 2000 scientists at the Oregon Regional Primate Research Center announced the birth of the first genetically engineered primate, named ANDi (for "inserted DNA" spelled backwards), a rhesus monkey whose cells contained the gene that makes jellyfish glow in the dark. The experiment was something

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[116] Hayes, Richard. Modified People.
<http://www.genetics-and-society.org/resources/cgs/200207_worldwatch_hayes.html>

of a flop; ANDi does not glow. Rodents implanted with the gene do however.[117] This evidence brings us to believe that someday, through enough experimentation, human genetic manipulation will indeed work.

Traditionally, human reproduction is supposed to be a natural process in which an egg is fertilized internally, slowly grows through an embryonic stage and eventually becomes a human child. This is the same process by which all other mammals reproduce and the way nature intended. Why is it necessary then to manipulate nature and take reproduction into the laboratories? *"We are compelled to decide nothing less than whether human procreation is going to remain human, whether children are going to be made to order rather than begotten, and whether we wish to say yes in principle to the road that leads to the dehumanized hell of Brave New World."*[118] If the technology of genetic manipulation were to advance as some scientists intend, the process of procreation will become more like buying a living, breathing, and feeling "designer baby" doll.

Genetic modification could ultimately lead to a separation of humans into two separate species. Princeton University microbiologist Lee M. Silver can see a day a few centuries from now when there are two species of humans: the standard-issue "Naturals," and the "Gene-enriched," an elite class whose parents consciously bought for them designer genes, and whose parents before them did the same, and so on for generations.[119] Silver foresees that by the year 2400 two separate species of humans will

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[117] Brownlee, Shannon. Designer Babies. <http://www.washingtonmonthly.com/features/2001/0203.brownlee.html>

[118] Untitled. <http://www.betterhumans.com>

[119] Sally Deneen, E Magazine, 2001

exist, as closely related as humans are to chimps. *"We can already see ways in the future where we're going to be able to manipulate and control the genes that we give to our children. It's just over the horizon. So all of these new technologies are going to change humankind as we know it."*[120] In his book Remaking Eden, Silver predicts that the two human species will be so dissimilar they will lose the ability to interbreed. Humans now carry around 46 chromosomes; according to Remaking Eden within a few centuries they will carry about 48 to accommodate added traits.

Currently it is possible to insert foreign DNA into mice, pigs and sheep. The only difficulties that still stand in the way of doing the same in humans are technical ones. By 2010 it is predicted that parents will be able to insure that their child will not grow up obese or turn out to be an alcoholic. By 2050 the ability to insert DNA vaccines may be a reality and vaccines for AIDS and HIV will be readily available.[121] As far as modifying athletic ability or personality traits, it may be several decades before the technology is developed. Present technology is too risky to attempt insertion of any type of foreign DNA insertion in humans because it could lead to mutations. Numerous techniques are being developed now to correct this difficulty. Experimentation requires failures in order to be successful in the long-run. In order to successfully insert DNA into humans several hundred trials must be attempted which would mean several hundred mutated babies or miscarriages. Nelson Wivel, who served on the National Institutes of Health's Recombinant DNA Advisory Committee, had this to say on the subject. *"The risks of gene-therapy will never be eliminated, and mistakes would be irreversible. Germ-line gene modification will always be associated*

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[120] Interview: Lee Silver. <http://www.pbs.org/wgbh/pages/frontline/shows/fertility/interviews/silver.html>

[121] Sally Deneen, E Magazine, 2001

with the risk of unpredictable genetic side effects, and for this reason it never should be approved for human use."[122]

All forms of prenatal testing run some physical risks to both the fetus as well as the mother. Whether prenatal testing for serious diseases is right or wrong is a fair question to debate, but whether genetic modification is right or wrong, knowing the risks associated with even the simplest types of prenatal screening, should not even raise the question. The answer is genetic manipulation is a risk that is not worth taking.

Human Cloning

What exactly is human cloning? Most people think of human cloning as something we see in science fiction movies to create armies of human "clones" or Dr. Evil "cloning" himself to make Mini-Me. That couldn't be farther from the truth however. Human cloning refers to a large field of completely unrelated procedures with three very different goals. The three types of cloning are: embryo cloning, Adult DNA cloning (reproductive cloning,) and Therapeutic cloning (biomedical cloning.) [123] Embryo cloning is a medical technique which produces monozygotic (identical) twins or triplets. It duplicates the process that nature uses to produce twins or triplets. One or more cells are removed from a fertilized embryo and encouraged to develop into one or more duplicate embryos. Twins or triplets are thus formed, with identical DNA. This has been done for many years on various species of animals; only very limited experimentation has been done on humans. Adult DNA cloning is intended to produce a duplicate of an

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[122] Untitled. <http://www.betterhumans.com>

[123] Human Reproductive and Therapeutic Cloning. <http://www.religioustolerance.org/cloning.htm>

existing animal. It has been used to clone a sheep and other mammals. The DNA from an ovum is removed and replaced with the DNA from a cell removed from an adult animal. Then, the fertilized ovum, now called a pre-embryo, is implanted in a womb and allowed to develop into a new animal. As of January 2002, it had not been tried on humans. It is specifically forbidden by law in many countries. There are rumors that Dr. Severino Antinori, an Italian embryologist, has successfully initiated a pregnancy through reproductive cloning.[124] Reproductive cloning has the potential of producing a twin of an existing person. Based on previous animal studies, it also has the potential of producing severe genetic defects. For the latter reason alone, many medical ethicists consider it to be an immoral procedure when done on humans. Biomedical cloning is a procedure whose initial stages are identical to adult DNA cloning; however, the stem cells are removed from the pre-embryo with the intent of producing tissue or a whole organ for transplant back into the person who supplied the DNA. The pre-embryo dies in the process. This type of cloning is strongly opposed by many religious groups due to the death of the pre-embryo. The goal of therapeutic cloning is to produce a healthy copy of a sick person's tissue or organ for transplant. This technique would be vastly superior to relying on organ transplants from other people. The supply would be unlimited, so there would be no waiting lists. The tissue or organ would have the sick person's original DNA; the patient would not have to take immunosuppressant drugs for the rest of their life, as is now required after transplants. There would also not be any danger of organ rejection.[125]

Certain ethical issues surround each type of cloning, but the major concerns are those surrounding adult DNA cloning. While the term cloning does not actually refer to

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[124] Human Reproductive and Therapeutic Cloning. <http://www.religioustolerance.org/cloning.htm>

[125] Human Reproductive and Therapeutic Cloning. <http://www.religioustolerance.org/cloning.htm>

making an identical copy of an existing human this method has the possibility of yielding such results. When asked his opinion on the future of human cloning, Lee Silver, professor of genetics at Princeton University, had this to say:

> *"I predicted that human cloning would be with us in 10 years and I still believe that is the case, because there is a demand among a small number of people for this technology to have babies. It's being driven by the marketplace. I think that, ethically, one should not use this technology until they are convinced that it is safe and efficient, shown with the use of animals. But I don't think that physicians around the world are going to wait for the confirmation that it's safe and efficient in animals."* [126]

On July 5, 1996 at the Roslin Institute Dolly, the first sheep successfully cloned from the cells of an adult, was born. Dolly was created by removing the genetic material from an embryonic cell of a Scottish Blackface sheep and replacing it with the genetic material from a six-year-old Finn Dorset sheep. Before the birth of Dolly it was believed that genetic material from adult cells could not be programmed to create new animals. Dolly lived a relatively normal life. She produced six healthy lambs through the natural mating process. Later in her life, although still middle ago of most healthy sheep, Dolly developed arthritis as well as a degenerative lung disease known as pulmonary adenomatosis. Shortly after veterinarians confirmed that Dolly had fallen victim of the lung disease she was euthanized and the world said goodbye to one of science's most popular icons. The real ethical battles surrounding Dolly didn't really begin until her premature death at the age of 6 in 2003. Many ethicists argue that Dolly died prematurely as a direct result of her being a clone. *"If there is a link, it will provide further evidence of the dangers inherent in reproductive cloning and the irresponsibility*

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[126] Interview: Lee Silver.<http://www.pbs.org/wgbh/pages/frontline/shows/fertility/interviews/silver.html>

of anybody who is trying to extend such work to humans."[127] They believe that since she was created from the genetic material of a six-year-old sheep that she was six when she was born. Her death at the age of six supports their argument. Most adult sheep live to be twelve-years-old; Dolly was six when she died. Add her six years of life to the six years of life of the genetic material used to create her and what's the total? Twelve years.

The possible physical damage that could be done if human cloning became a reality is obvious when one looks at the sheer loss of life that occurred before the birth of Dolly. Less than ten percent of the initial transfers survive to be healthy creatures. There were 277 trial implants of nuclei. Nineteen of those 277 were deemed healthy while the others were discarded. Five of those nineteen survived, but four of them died within ten days of birth of severe abnormalities. Dolly was the only one to survive. If those nuclei were human the experiment would be considered catastrophic.

Opposition to human cloning is coming from a few different angles. Medical specialists oppose cloning for a variety of reasons all of which spring from the fact that not enough is known about the effects cloning will have on a human being. First of all there is no guarantee that the first cloned humans will be normal. The fetus might suffer from some disorder that is not detectable by ultrasound. They may be born disabled. Disorders may materialize later in life. Such problems have been seen in other cloned mammals so the possibility of them existing in humans is pretty good. Current speculation is that the cloning process seems to create random errors in the expression of individual genes. The egg must have its genes reprogrammed in minutes or hours during the cloning process. Ova normally take years to ripen naturally in the ovaries. It appears

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[127] Dolly the Sheep Clone Dies Young. <http://news.bbc.co.uk/1/hi/sci/tech/2764039.stm>

that the extremely fast rate of programming can produce random errors in the clone's DNA. Another medical reason is one that is very important when the life of Dolly the sheep is analyzed. The idea is that cells have a predetermined life span built into them. This would mean that adult cells used to create babies would actually lead to the birth of a baby with adult-aged cells. Cloning experiments on mice in Japan show damage to immune systems, risks of death from pneumonia, liver failure, spontaneous abortions and abnormal births. Ten out of Twelve cloned mice born apparently healthy at birth lived less than 800 days.[128] This is such a concern because it makes scientists fear that the lifespan of clones may be severely reduced. There is a fundamental medical principle that one should do no harm. At the present time experimental human cloning would do harm. Cloning may also put the pregnant mother at risk more so than natural pregnancies. In one US study using cows, four of twelve surrogate mothers die from pregnancy complications. Social ethicists have raised a few major concerns as well. There is fear that large scale cloning could deplete genetic diversity. Diversity is what drives evolution and ultimately prevents humans from becoming extinct.[129] Another fear of social ethicists that seems a little far-fetched is the utter uselessness of the male species. Dolly was created from the DNA of one adult ewe's body and the egg from another. There was no sperm involved in the fertilization of the zygote. Without the need for sperm in reproduction there is no genetic need for males to exist. Questions have also been raised about the effect cloning would have on parent-child relationships. A child born from adult DNA cloning from one parent would, in effect, be a delayed twin of that

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[128] Korean scientists claim human embryo cloning success – for research.
<http://www.globalchange.com/clonenews.htm>

[129] Dolly the sheep dies young. <http://news.bbc.co.uk/1/hi/sci/tech/2764039.stm>

parent. As that has never happened before there is the fear that it may lead to emotional difficulties. There is opposition to cloning coming from religious groups as well. These issues only would apply to those who are religious as those who are not would not be interested in the ethics of religion. Religious pro-life supporters believe that a fertilized ovum is a human person. They believe that when the nucleus is removed during cloning the person is in effect murdered. One of the greatest fears religious groups face is the belief that cloned humans are born without souls.[130] It is difficult for religious ethicists to make a strong case against human cloning however, due to the fact that only a small percentage of the population is actually religious. Another problem facing religious ethicists is that religious beliefs cannot be preserved into law, making any point they might have null when it comes to passing regulatory laws. This means then that the major issues surrounding human cloning that affect the mass population are those suggested by medical and social ethicists.

Animal rights groups also oppose cloning but for different reasons that most. They are opposed to cloning for the fact that thousands of animals are horribly disfigured and killed as humans try to perfect the unethical science of cloning. It is harder to convince that non-human cloning is wrong and unethical, but many would agree the two are directly related. The cloning of a non-human species subjects them to unethical treatment purely for human needs. Tradition has long held the belief that the treatment of animals should be guided by different ethical standards than the treatment of humans. Animals have been seen as non feeling and savage beasts for as far back as history stretches. Humans have no problem with seeing animals as objects to be used whenever

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[130] <u>Human Reproductive and Therapeutic Cloning.</u> <http://www.religioustolerance.org/cloning.htm>

it becomes necessary for the advancement of our own species. Where is the line drawn between human and non human? If a primate was cloned so that it grew human lungs, liver, kidneys, and heart., what would it then be? Just a holding tank in place until it proved itself useful by dying when the organs were needed for human transplants. What if we were to learn how to clone functioning brains and have them grow inside of chimps? Would non-human primates who carried one or more human genes as the result of transgenic technology, be defined still a chimp, a human, a subhuman, or something else entirely? And if humans were to carry non-human transgenic genes, would that alter our definitions and treatment of this new breed of human? The sheer loss of life in both humans and non-humans is enough to prove that cloning would be a foolish endeavor, whatever the cause.

An abnormal baby born from cloning would be a nightmare come to life. One particular worry is that the genetic material used from the adult, with an age of about 30, would result in a baby born with 30 year old genes, in effect making the baby 30 years old when it is born. Early attempts to clone animals caused disfigured monsters with severe mutations and abnormalities. While the kinks of early animal cloning were worked out over time, the fact of the matter is that there were thousands of unsuccessful attempts before the science was figured out. Humans have different genetic structures than animals. Therefore if and when human trials were to begin who is to say we will not create horribly disfigured human clones as we did with animals? There is no way to do the trial and error method when working with human lives. If a baby is presumably imperfect while growing in the womb it will be destroyed raising issues of abortion. There would still be the possibility of a baby being born normally and developing some abnormalities after birth, similar to Dolly the sheep that developed arthritis and a severe lung disease that many say is linked to cloning. It may take as many as 20 years or more for some abnormalities to develop in babies who may be born "healthy" from reproductive cloning. Cloning humans is too hit-or-miss. Even if a single baby were born healthy and free of all mutations there would be a string of babies born with severe abnormalities. That also just speaks of the babies that are actually born. There are still the disfigured and abnormal fetuses that were either spontaneously aborted or destroyed by scientists who knew of the danger of what they were creating.

Would a clone of myself be my son or rather my twin brother? In actuality the clone would be just that – a new distinction of individuals known as clones.[131] Clones would, in genetic terms, be considered as identical twins of whoever donated the genetic material to create them. Therefore a child could grow up knowing that her mother is her genetic sister, her grandmother is her mother and her father is her brother-in-law. This would create unbearable pressures on any child trying to establish their own identity knowing that when their mother looks at them she sees herself growing up, or even worse knowing that he or she is the clone of a dead brother or sister. A child born of cloning would not be identical in every way despite the best efforts of parents and scientists, which may result in the parents mistreating the cloned "replacement" for their deceased little boy or girl. Mistreatment doesn't have to necessarily come in the form of physical or mental abuse, but just enough that the child would grow up in a stressful environment.

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[131] Reasons against cloning. <http://www.globalchange.com/noclones.htm>

That would be enough to place huge emotional pressures on the development of the child and as a result the child would face very serious emotional risks.[132]

Cloning is facing opposition from those who say it would be an industrial process. There are arguments to back this up. Creating a human clone can be done without one individual having to have a relationship with another, thereby contradicting the idea of humanity. Humans should not be created like automobiles or other machines produced on an assembly line. Humans should be created as the result of two parents falling in love with one another and going through the natural process of procreation. Cloning is similar to genetic manipulation when it is looked at as a manufacturing process.

In my personal opinion the greatest risk concerning human cloning is the abuse of technology. Not just in the sense of creating human baby clones, but on a larger scale. What if some egotistical person with enough money decided they wanted to make an army of clones of themselves? What would have Hitler done with the knowledge of cloning if it were available to him in the 1940's?[133] Hitler is not the only person who would have looked to abuse this technology. Every generation has leaders looking for an advantage and would exploit any technology they could in order to get it. Every bit of new knowledge surrounding cloning is taking another step towards this possibility. There is no way to create cloned embryos without somebody taking the idea one step further and bringing reproductive cloning into the picture. The technique to create cloned babies is the same as it is to create a cloned embryo so the two come hand-in-hand.

In recent weeks Korean scientists made a ground-breaking announcement: they had successfully cloned healthy human embryos, removed embryonic stem cells, and

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[132] ibid.

[133] Reasons against cloning. <http://www.globalchange.com/noclones.htm>

grew them in mice. Scientist Woo Suk Hwany of Seoul National University is the man credited with the scientific and medical breakthrough. The Korean scientists say they are personally opposed to the abuse of human cloning technology to produce human babies, but their advances have paved the way for scientists who do wish to clone humans. Dr. Patrick Dixon, an author and expert in ethics of human cloning, had this to say about the announcement:

> *"Except in tissues like the brain, there are huge problems with rejection of embryonic stem cells if they are introduced into adults. It is very difficult to grow them properly and very difficult to control them. The idea that this offers a breakthrough is based on a scientific nonsense. But in this supposedly spectacular benefit lies a serious risk that this technology will be abused."*[134]

Dr. Dixon warned that developments in embryonic stem cell research would be "handing a gift" to those scientists who wish to abuse the technology and take it to the extent of cloning human babies.[135]

The announcement made by the Koreans reinforces the attempts of Dr. Panos Zavos, a fertility specialist based in Kentucky, to create the first cloned human baby. Dr. Zavos' work is done alongside Dr. Severino Antinori. Dr. Zavos has made an ongoing commitment to bring a cloned baby into the world, but he acknowledges that the baby would suffer critical medical problems.

According to the President's Counsel on Bioethics there are several general concerns pertaining to human cloning. Below is a paraphrased and simplified version of

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[134] Korean scientists claim human embryo cloning success – for research. <http://www.globalchange.com/clonenews.htm>

[135] ibid

the President's Counsel of Bioethics staff working paper 3B – arguments against human cloning:

Safety and Health of Children and Mothers

The first of these is a concern raised by nearly everyone on all sides of the cloning debate, the safety of all involved. Almost no scientists will argue that cloning is presently safe enough to attempt on human beings, although there are some exceptions. Examples of cloning experiments in other mammals strongly suggests that human reproductive cloning is, at least for now, far too risky to attempt. Safety concerns revolve around potential dangers to the cloned child, as well as to the egg donor and the surrogate mother.[136]

Consent

Beyond physical safety, the prospect of reproductive cloning also raises concerns about a potential violation of the rights of individuals, particularly through a denial of the right to consent to the use of one's body in experimentation or medical procedures.[137]

Eugenics and Enhancement

> *"The darkest side of eugenics is of course familiar to any student of the twentieth century. Its central place in Nazi ideology, and its brutal and inhuman application by the Third Reich, have put that science largely out of favor. No argument in today's cloning debate bears any resemblance to those of Hitler's doctors. But by the same token, it is not primarily the Nazi analogy that should lead us to reject eugenics."*[138]

It is a less dark side of eugenics that actually threatens to confront us. This side is well-intentioned, but could prove at least as dangerous to our

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[136] Arguments against reproductive cloning. <http://www.bioethics.gov/background/workpaper3b.html>
[137] Arguments against reproductive cloning. <http://www.bioethics.gov/background/workpaper3b.html>
[138] Arguments against reproductive cloning. <http://www.bioethics.gov/background/workpaper3b.html>

humanity. The goal of "better" and "healthy" children combined with modern genetic techniques threatens to blur and ultimately eliminate the line between therapy and enhancement.

Eugenics may also open the road to a new inequality, as has been previously stated, by which only those who can afford it can gain advantages for themselves and their descendants into future generations.[139]

Respect for Nature

Cloning also raises a number of concerns about humanity's relation with the natural world. We must beware of the unintended consequences of applications of human power and, in the case of human cloning, "ill will," particularly over nature. Natural systems with the complexity of the natural environment do not respond well to human intervention, and one can hardly think of a more complex system than that responsible for human reproduction. This suggests that geneticists should not pretend to understand the consequences of their alterations of human nature, and therefore should not be so rash as to clone a human child.[140]

Manufacture and Commodification

Reproductive cloning could also represent an enormous step in the direction of transforming human procreation into human manufacturing. In natural procreation, two individuals come together to give life to a new individual as a consequence of their own being and their own connection with one another, except in accidental cases, rather than merely of their will. They do not design the final product, they give rise to the child of their embodied selves, and they

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[139] Arguments against reproductive cloning. <http://www.bioethics.gov/background/workpaper3b.html>
[140] ibid

therefore do not exert control over the process or the resulting child. They beget something that is in essence like themselves; they do not make something that is in essence their own. The product of this process, therefore, stands beside them fully as a fellow human being, and not beneath them as a thing made by them with only their own purposes in mind. A manufactured thing can never stand beside its human maker as an equal, but a begotten child does stand equally beside its parents. The natural procreative process allows human beings - through the union of male and female - to make way for fellow human beings, to whom they give rise, but whom they do not make. It thus endows each new generation with the dignity and freedom enjoyed by all that came before it.[141]

Identity and Individuality

Similarly to procreation transforming into human manufacturing, cloning may possibly create broader and more serious concerns about the mental and emotional life and the personal and social relations of the individual produced by a reproductive cloning procedure. These concerns would apply even if cloning was only conducted on a small scale. The natural procreative process is uniquely capable of endowing new human beings with a combination of family bonds on the one hand, and independence and individuality on the other. By nature, every child is tied to two biological parents, and that child's unique genetic identity is determined by what is essentially a chance combination of these parents' genotypes. Each child is thus related equally and by the closest of natural bonds to two adult human beings and yet each child is genetically unique. Both these characteristics, and the procreative nature of humanity from which they arise and

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[141] Arguments against reproductive cloning. <http://www.bioethics.gov/background/workpaper3b.html>

to which they point, help give shape to the psyche of each of us, and to the human institutions that allow us to thrive. A cloned child would, in turn, miss out on the relationships that shape and mold each of our individual psyche which would directly affect their individuality.[142]

Family and Procreation

Just as the cloned individual's sense of individuality may be confused by his origin, his connection to others, and particularly to their own family, may become confused as well. This effect could be mirrored and amplified in the effect that cloning might have on the institution of the family, and the way in which individuals and communities come to think of procreation.[143]

Impact on Society

Cloning is a human activity, which affects not only those who are cloned or who are clones, but also the entire society that allows or that supports, and therefore that engages in such activity.

> *"The question before us is whether reproductive cloning is an activity that we, as a society, should engage in. In addressing this question, we must reach well beyond the rights of individuals, and the difficulties or benefits that cloned children or their families might encounter. The question we must face has to do with what we, as a society, will permit ourselves to do. When we say that "reproductive" cloning may erode our respect for the dignity of human beings, we must say that we, as a society that engages in cloning, would be responsible for that erosion. When we argue that vital social institutions could be harmed, we must acknowledge that it is we, as a society that clones, that would be harming them. We should not ask if "reproductive" cloning is something that some people somewhere should be permitted to do. We must ask if cloning is something that all of us together should want to do or should allow ourselves to do. Insofar as we permit cloning in our society, we are the cloners and the cloned, just as we are the society affected by the process. Only when we see that do we*

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[142] Arguments against reproductive cloning. <http://www.bioethics.gov/background/workpaper3b.html>
[143] Arguments against reproductive cloning. <http://www.bioethics.gov/background/workpaper3b.html>

> *understand our responsibility in crafting a public policy regarding human reproductive cloning."*[144]

There must be policies put in place to regulate or ban practices of genetic engineering. There need to be both domestic and international policies in place to ban human cloning as well as genetic modification. Also there must be strict regulations on any other genetic technologies while at the *same "affirming the many beneficial applications of genetic science - in diagnostics, therapeutics, pharmaceutical development, and other medical fields – and to ensure that these are available to all people, regardless of economic status or geography."*[145] In order for policies to be put in place, there must be an organized effort to make it happen. This can only happen if new levels of awareness and organization are raised. In order to protect the integrity of the human species this is absolutely necessary. "*Our common humanity is at stake."*[146]

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[144] ibid

[145] Modified Humans.
<http://www.genetics-and-society.org/resources/cgs/200207_worldwatch_hayes.html>

[146] ibid

Conclusion

Both sides of the prenatal screening argument present many valid points, such that if one side was looked at without the other it may seem like a clear cut case. The fact that each side can present so many ideas in favor of their case is what causes prenatal screening to be a topic that is heavily debated. In addition to this, the judgment of someone trying to make a decision about how they feel about prenatal screening is clouded by the fact that the future of screening is still unclear, and being behind prenatal screening now may not stand for the same thing as it does in twenty years. Still, with all these facts, many people believe one side or the other.

The ideas that cause someone to sway their beliefs to one side or the other can vary from person to person. It could be a personal experience, maybe one where prenatal screening was directly involved in their life, in either a positive or negative way. It could be their religious belief, or their stance on the abortion issue that causes them to feel one way or the other. It could even be something as simple as a movie they watched, a book they read, or a conversation they had. The decision itself is something that varies from person to person, as does the level of education that is involved in this decision. It is only by looking deeply into both sides of the issue, and gaining as much knowledge as possible on the topic in question can someone make a completely educated decision.

Still, prenatal screening is a debate like few others. It is one where some assumption is inevitable, since the path into the future that prenatal screening will take is an integral part of the debate. It is in this way that it is impossible for either side's argument can be complete, since both sides are assuming some facts about the future. A pro-prenatal screening argument would pose that screening will someday lead to disease and disorder prevention; while an anti-prenatal screening argument would pose that screening will someday lead to designer babies and people playing God. Neither side can be sure of these futures; it is in this way that neither side's argument can be considered concrete.

Another reason that the argument of screening is one that does not lend to easy conclusions is that some people make their decisions assuming the decisions of others. Specifically, some people are against screening because they feel it may lead to abortions. Furthermore, it is not really the screening that they are against, but the abortion itself. There are some people who oppose anything they feel could cause unjust loss of human life, and they view prenatal screening as one of these things. Whether or not this is true is based on the assumption that prenatal screening leads to abortion, which is not necessarily true.

Basically, the conclusion to both arguments is that is impossible to set precedence, especially one that would make a statement that one side is right and the other is wrong. Each person must form their own individual stance based on their own personal situation, and should strive to obtain as much information as possible about both sides when doing so.

Prenatal screening is a topic that transcends the medical field into almost all major areas of debate. Religion is always involved in any medical process that some view as humans "going to far" or "playing God", and prenatal screening is no exception. Those who feel that this is a good thing would do so most likely because they feel that religion is that entity that keeps the medical field in check. They feel positively about this because they believe that it would do the human race good to not tamper with the way God intended the world to be.

On the other side of this argument are people who believe that the medical field is being held back by religion, and this slowing of the development of technology is costing people there lives. This is a broad view of the argument of religion versus technology, which prenatal screening is a smaller part of. Those who concern this argument of religion slowing technology and costing lives with prenatal screening do so assuming that prenatal screening technology will someday lead to the development of technology that will save lives.

Other areas of debate that prenatal screening can become involved in are law and politics. Legislation must be formed to deal with new technologies, as well as be constantly updated to deal with new developments. These laws are made by people of course, and these people are put on the spot about their beliefs, forced to choose one way or the other. It is in this way that it is most important for lawmakers to be educated about both sides of the prenatal screening debate, since many people use the law as a basis for their beliefs, assuming they are just.

There are important ideas brought forth by both sides of the argument, but there are too many parts of both sides that are based on assumptions. These assumptions rely on both the future, and on assuming the reactions that prenatal screening may cause in other people. For people who have to make the decision of whether the pro or con side sounds better, such as lawmakers, insurance companies, and doctors, they must fill in these blanks for themselves, but it is impossible for anyone to designate one side as truth. The only thing that can be done is wait and see what the future holds.

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