### A Word to Sheepdogs

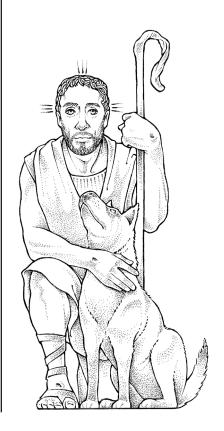
Pastors are regularly asked to provide counsel and care to people facing increasingly complex ethical decisions occasioned by the newer medical technologies. It seems to me that these situations are fraught with danger. If we clam up and say nothing we may lend tacit approval to sin. On the other extreme, if we jump in with a "thus says the Lord" on something we know nothing about we may unwittingly burden tender consciences.

Tyler Arnold does us all a favor in this most enlightening essay on the rapidly developing front of genetic engineering, with special reference to the recently developed CRISPR technology for genome editing. His careful research and biblically-informed pastoral heart help guide us safely through these unknown waters, avoiding either the Scylla of silence or the Charybdis of ignorant pronouncements.

After a review of pertinent literature regarding this technology and its use and abuse, he helpfully provides an example of quality pastoral teaching in his summary of how the men and women in his Bible class evaluated the application of genetic engineering before and after his instruction. Pastors looking for guidance on how to faithfully guide people in this complex area of bioethics will find plenty of it in this essay.

That's the thing about God's word: it serves as a light to our path and a lamp for our feet as we navigate the precarious path of ethical uncertainty; thank God, it gives light to simple folk — like us! (Ps 119:130)

Dr. H. L. Senkbeil



# Genetic Engineering: Ethical, Theological, and Pastoral Considerations

Pastor Tyler C. Arnold

#### Introduction

Imagine a world where every man, woman, and child are routinely tested and treated for a myriad of genetic disorders in order to ensure that the human race maintains the highest level of sustained health possible. Imagine if diseases like cystic fibrosis, sickle-cell anemia, Tay-Sachs, Alzheimer's, ALS, as well as thousands of exceedingly rare illnesses that afflict no more than a few individuals became virtually extinct as a result of effective and inexpensive genetic editing.¹ Surely if such advances became a reality, the world would not hesitate to sing the praises of these scientifically-engineered miracles that offer to eliminate, or at least significantly lessen, human suffering.

With the hope of eliminating disease and disability also comes a host of other questions and legitimate ethical concerns regarding alterations to the human genome. For those who are not yet born, as well as newborn babies, what sort of rights should they be given as independent human beings? What about the possibility of genetic discrimination? Some may think a particular genetic code is defective while others consider it normal. With that, who determines which genetic codes are considered undesirable or

<sup>&</sup>lt;sup>1</sup>There are more than 6,000 known single-gene disorders that occur in about 1 out of every 200 births. These disorders are known as monogenetic disorders (disorders of a single gene). https://www.medicinenet.com/genetic\_disease/article.htm

which ones are to be preferred? Where does mankind draw the line when it comes to genetic tinkering? Few would argue against preventing disease — but what happens when parents are given the opportunity to design aesthetically beautiful, genetically superior babies? New technologies in the field of genetic engineering have opened a Pandora's Box of endless genetic modification possibilities that reach beyond editing for curative purposes. For that reason, it is imperative to explore a broad survey of the ethical, theological, and pastoral issues in light of technologies that have opened up new avenues in somatic cell and germline cell genetic editing.

This paper will first explain the recent genetic-editing technology called CRISPR/Cas9, which has opened up a new world of scientific discovery within the realm of genetic engineering, then discuss its attending implications on somatic and germline cell editing. Secondly, it will explore the ethics of genetic editing within these two different cell types, in light of therapeutic and enhancement purposes. Finally, it will address the theological and pastoral matters that coincide with these new genetic editing considerations, how they will affect the Christian life and subsequently the church-at-large.

These advancements will certainly filter down into the lives of parishioners, and like so many matters involving ethical and theological considerations, it is pastorally advantageous to address them before they become commonplace. To demonstrate this, I discussed gene editing technology and its implications with the Sunday morning adult Bible study class at Christ Lutheran Church in Platte Woods, Mo. I began this instruction

by asking them to reflect on five general questions about genetic editing, and then observed any changes in opinion after they had learned more. The survey and results appear in the appendix of this paper. I will be referring to the survey results along with further conversations that happened during the Bible study class primarily within the second and final portions of this paper.

#### CRISPR/Cas9

The term "Genetic Engineering" was coined (in 1965) for what has come to be a wide range of techniques by which scientists can add geneticallydetermined characteristics to cells that would not otherwise possess them.<sup>2</sup> Since then, many different genetic modification types of technologies have come into use. Currently, a number of these technologies are available, or in development, to modify genes.3 However, the most recent genome-editing tool to be developed is also presently the most efficient and inexpensive. It is called clustered regularly interspaced short palindromic repeat-associated system or CRISPR/Cas9. This bacteriaderived system uses RNA molecules that recognize specific human DNA sequences. "The RNAs act as guides, matching the nuclease to corresponding locations in the human genome. CRISPR/Cas9 (CRISPR) is the simplest genome-editing tool because it relies on RNA-DNA base pairing rather than the engineering of proteins that bind particular DNA

<sup>&</sup>lt;sup>2</sup>Joanna Smolenski, "CRISPR/Cas9 and Germline Modification: New Difficulties in Obtaining Informed Consent," *The American Journal of Bioethics* 15, no. 12 (2015): 35.

<sup>&</sup>lt;sup>3</sup>These technologies include mitochondrial transfer, somatic-cell nuclear transfer, zincfinger nucleases, and transcription activator-life effector nucleases among others.

sequences."<sup>4</sup> This system has many advantages over other genetic modification technologies. As previously mentioned, CRISPR is relatively simple and inexpensive to produce, and thus has been produced over 45,000 times and sent to more than 22,000 laboratories in at least 61 different countries.<sup>5</sup> Compared to other gene modification methods, CRISPR does not require much of the high-priced equipment that other gene modification methods need.

The drawback to using CRISPR is that research has shown it can make off-target cuts in cells upward of 60% of the time.6 Even when the cuts on mutated genes are successful, the overall effect can still be negative. For instance, one genetic alteration might successfully remove heart disease, but then activate a gene that triggers diabetes. Some scientists particularly fear alterations to human embryos because of the possibility of unknowable, serious, and debilitating health issues for future generations. Given the unknowns of the cutting-edge technology, some scientists question whether CRISPR is understood enough to be introduced clinically; and though CRISPR will never be 100% safe, they debate whether it will ever be safe enough: "Though CRISPR has the precision of a genetic scalpel, changes

Although CRISPR is considered one of the most promising technologies to be developed in gene therapy, it still brings with it substantial ethical issues. Jeffrey Steinberg, director of The Fertility Institutes says, "Once you're able to look at and identify chromosomes in embryos, then you can study everything in that embryo and the term 'everything' keeps expanding. People are going to be able to come in and say, 'I don't want my baby to have Down syndrome, I want my baby to be a girl, I want my baby not to carry the breast-cancer gene, and I want my baby to have blue eyes."8 While these requests are not all created equal, and there are varying degrees to which ethical principles apply, they demonstrate the potential enormity of effective and inexpensive genetic editing possibilities.

### Somatic Cells and Germline Cells

Since the advent of genetic engineering, scientists have faced the ubiquitous issue of whether or not editing should be permitted to modify the genes of human germline cells or be limited to somatic cells. Somatic cells are any body cells that are not reproductive gametes (egg cell or sperm cell): they are called adult cells and "are usually differentiated and do not differentiate further in vitro." Somatic engineering refers to the manipulation of genes within specific organs or tissues of

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to off-target loci make the results unpredictable."7

<sup>&</sup>lt;sup>4</sup> Somoleski, CRISPR/Cas9 and Germline Modification, 35.

<sup>&</sup>lt;sup>5</sup> CRISPR: The Gene Editing tool Revolutionizing Biomedical Research, 60 Minutes news report aired on April 29, 2018. Also at https://www.cbs.com/shows/60\_minutes/video/dldyXroziO4KUSRu\_98VLALNMxtt7c Xg/crispr-the-gene-editing-tool-revolutionizing-biomedical-research/

<sup>&</sup>lt;sup>6</sup>Somoleski, CRISPR/Cas9 and Germline Modification, 37.

<sup>&</sup>lt;sup>7</sup> Tami Ball, "The Ethics of Genetics," AMWA Journal 32, no. 4 (2017): 182.

<sup>&</sup>lt;sup>8</sup> Quote found in Melinda Wenner Moyer, "Infant Possibilities," *Popular Science, August, 2014: 84.* 

<sup>&</sup>lt;sup>9</sup> Tami Ball, The Ethics of Genetics, 182.

an organism that affect only that tissue, and do not change the original genetic information within reproductive cells that can be passed on to future generations. Applications such as gene therapy to treat existing genetic disorders fall under the category of somatic cell engineering. In contrast, germline cells are reproductive cells. Editing these cells will change the genetic code for future generations. Cloning and In Vitro Fertilization (IVF) are both examples of germline engineering.

Ethically, somatic and germline cell genetic editing must be addressed separately because the impact of each creates a variance in ethical dilemmas. For example, an individual with a genetic condition or disease who undergoes somatic gene therapy may be taking a risk, but the probability that this decision would impact the whole of society is minimal. Germline engineering, on the other hand, changes the genetic makeup of both the individual and future generations, assuming the individual reproduces. Germline manipulation has the potential to create exponentially more positive and negative effects in the genetic makeup of humans compared to somatic engineering. Brent Waters describes the differences in outlook between these two cell types and modifications therein when he says:

In general, somatic therapeutic modification is judged to fall within the bounds of customary medical practice so long as such stanthat may be noted briefly: it would alter the genomes and identities of future persons who are unable to give or withhold their consent; it targets people with disabilities, promoting greater social ostracism; it would create more homogeneous societies; it places an unwarranted confidence on technology to improve the human condition; genetically enhancing offspring is both morally wrong and would create unfair competition in future generations between the enhanced and unenhanced.10

Waters touches on the primary ethical challenges facing germline modification. He and other ethicists are generally more accepting of somatic gene therapy, to which we now turn our attention.

### **Ethical Issues of Somatic Cell Therapy**

Somatic cell gene therapy is primarily viewed as an acceptable means of curative treatment since it focuses on the needs of only that particular patient. If technology provides the means to find a mutated gene that causes something like cystic fibrosis, and we could successfully treat or modify that gene in order prevent that disease, it would appear logical that such an outcome would be worthy of support. Gilbert Meilaender maintains that, "the moral questions raised by somatic cell therapy are less far-reaching, and they call for caution and a willingness to distinguish acceptable from unacceptable aims of therapy."11 Meilaender takes the focus of ethical questionability off of the actual method of somatic gene therapy and places it onto the

man Germ Line Genetic Modification," Chris-

tian Bioethics 18, no. 2 (2012): 172.

10 Brent Waters, "Christian Ethics and Hu-

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dard principles as safety, consent, and autonomy are not violated. As to germline modification, there are several prominent objections

<sup>&</sup>lt;sup>11</sup> Gilbert Meilaender, Bioethics: A Primer for Christians (Grand Rapids: Eerdmans, 2013), 44.

shoulders of human intent: the *modus operandi* of the technology is not so much the problem as much as the way it may be used.

Yet even though the ethical dilemmas of somatic cell genetic editing for therapeutic reasons are limited, the actual medical procedure is still not without its challenges. In 1999, for instance, a young man named Jesse Gelsinger participated as a research subject in a genetic therapy experiment aimed at treating inherited diseases of the liver at the University of Pennsylvania. Complications arose as a result of the treatment and Jesse eventually died of a blood clotting disorder caused, evidently, by the virus used as a vector to insert a corrective gene<sup>12</sup> — an example of how gene therapy can help one thing but hinder another. Even with its risks, the general population might favor somatic cell gene therapy since new technologies such as CRISPR continue to show promise as an effective, safe, and inexpensive way to cure disease or reverse disability.

One will struggle to find a biblical mandate against the ethical use of somatic cell gene therapy when the aforementioned therapy is used for curative purposes on the single individual it is designed to help. Some argue that our genetic code is sacred and thus should remain unaltered. Ted Peters calls this *the gene myth*, which he defines as a thought structure, a set of conceptual assumptions about reality that frames and filters the cultural reception of new scientific knowledge.<sup>13</sup> Peters maintains that, as those created in

the image of God,14 human beings are defined and have their intrinsic identity in so much more than genetic code. God's children are not body and soul (nephesh), separate and distinct; they are souls fearfully and wonderfully made together by the Master Architect, and "soul" includes all aspects of being. Therefore, Peters and others move beyond the idea that our genes determine our identity before God and conclude that there are therefore very few reasons to abrogate somatic cell gene therapy. In fact, one could conclude that our Christian responsibility is to encourage developments in this area, seeing them as a mark of Christian stewardship. 15

I asked members of Christ Lutheran Church whether or not they would use somatic cell gene therapy editing if it were safe, effective, and inexpensive and 53% (23) of the respondents said they might possibly use it (Figure 2).16 A combined 33% (14) more of those surveyed said that they probably or definitely would use it. With only 12% (5) of the respondents saying they would not use gene therapy on themselves, a majority of those surveyed did not seem to have an ethical issue with its use. After further discussion within Bible class, many of those who said they "might possibly" use it answered this

<sup>&</sup>lt;sup>12</sup> Meilaender, Bioethics, 42.

<sup>&</sup>lt;sup>13</sup> Ted Peters, *Playing God: Genetic Determinism and Human Freedom (New York: Routledge, 2003), 9.* 

<sup>&</sup>lt;sup>14</sup> This paper recognizes that the "image of God" is defined differently in different theological systems. For the purpose of this discussion, it is to be understood not in the sense of original righteousness, but that "we still possess the unique dignity (or worth) as those who were created in the image of God" (Small Catechism Explanation, 2017 edition, p. 140).

<sup>&</sup>lt;sup>15</sup> D. Gareth Jones, Valuing People: Human Value in a World of Medical Technology (Carlisle, Cumbria UK: Paternoster Press, 1999), 138.

<sup>&</sup>lt;sup>16</sup> Appendix I is the actual survey. Appendix II is the results of the survey.

way because they were afraid there might be an ethical issue with using somatic cell gene therapy. After further discussion, many of those that answer this way mentioned that they would change their answer to "probably" or "definitely."

# Ethical Issues of Germline Cell Therapy

At present, germline gene modification in its current state has no therapeutic benefits. Therefore, any research done in this domain is primarily experimental in nature.<sup>17</sup> However, the likelihood of its future development for clinical use should encourage us to consider its ethical issues now. The primary ethical issue is that germline cell therapy no longer deals with one single person in bodily form, but instead, "cuts to the core of the identity not just of one person but also of his descendants. If anything amounts to 'playing God' illicitly, germ cell modification might

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<sup>17</sup> Smolenski, CRISPR/Cas9 and Germline Modification, 36. "In February 2017, a report by the US National Academy of Sciences was widely seen as providing a green light for genetic modification of human embryos. Shortly thereafter, Shoukhrat Mitalipov of Oregon Health and Science University became the first researcher to report creating genetically modified human embryos in the United States. Three Chinese researchers had publications that preceded Mitalipov's, but, due to editing errors and incomplete make-up of the modified gene, they had concluded that genetic modification using CRISPR was not yet safe for clinical use. Mitalipov did not encounter these problems, but he never wished to implant the modified blastocysts and destroyed them at the 8-cell stage. In response to this report, the U.S. Congress instructed the FDA to withhold approval for any study that intended to produce a baby from a modified embryo. This did not, however, preclude it from happening in another country without such a ban." Ball, The Ethics of Genetics, 182.

seem to."18 While correcting a defect is the goal, and maintaining that correction would not appear wrong, there may be unforeseen risks involved for future generations. Since we are both free, self-determining beings and creatures of God, we should not only be asking ourselves if we can make use of germline genetic therapy but if we should. Some limits on human finitude should be respected, especially when others will eventually, involuntarily be affected. It is also vital to consider that, although disease and disability are unfortunate, they are not hostile to the human condition, but necessary and definitive features of what it means to be a creature. The role of medicine is not to assist humans to overcome their finite limits, but to help them come to terms with their finitude.19 Disability and diversity, then, are not foreign constructs that must be overcome in order to be considered whole or complete. No, rather, being fearfully and wonderfully made as God's image bearers include certain limitations that simply need not be remedied. With this in view, human disability and diversity, two perceived individual and cultural defects that could potentially be greatly reduced or even eliminated through germline genetic therapies, needs further exploration.

### Germline Therapy: Disability/ Diversity and Discrimination

The primary goal of germline genetic therapy is to reduce or eliminate diseases or disabilities through genetic editing prior to the birth of children. Germline therapy is recommended by scientists over somatic because

<sup>&</sup>lt;sup>18</sup> Meilaender, Bioethics, 43.

<sup>&</sup>lt;sup>19</sup> Waters, Christian Ethics and Human Germ Line Genetic Modification, 181–182.

it has the greater "forward" hope for the sake of beneficence.20 Today, doctors commonly test prospective parents for gene mutations that could possibly be passed on and cause a disease or disability in their children. With the potential to search out and cure every known genetically induced disease, however, comes a host of other issues that need to be considered. If we could begin today to correct all genetic mutations that lead to disease, what would this say about the current disabled community? How would culture and society begin to treat them if there were fewer disabled people? Would it have an effect on those who are not disabled? These and many other questions are still open for debate.

In response to the enthusiasm for these new technologies, one needs to look at the deeper issues that will surely result from the frenzy to make mankind free from genetic defect. For instance, Rosemarie Garland-Thomason mentions that, instead of understanding disability merely as a tragedy to be overcome or eliminated, we should recognize it as a valued resource to be conserved.<sup>21</sup> Consider how the disabled teach the nondisabled how to carry out God-given vocations of service, underpinning narratives that unite the entirety of community. Also, consider how disability is an ethical resource

because the existence of disability requires us to be open to "the unbidden" and be creative and flexible in our relation to the world. Likewise, disabilities remind and prepare us for the inevitable growing into disability through the progression of age.22 Although these might not seem like "good enough" reasons to avoid remedying life-altering diseases through genetic editing, germline genetic alterations for therapeutic purposes have far-reaching cultural considerations that need to be taken into account since they will have an effect on how we are given to serve those in need.23 Each person with a disability is to be treated as someone who is "imaged" in God's likeness since they too retain this image even in the midst of disability. Martin Luther sums it up nicely when he says, "We still call a leprous human being a human being even though in his leprous flesh everything is almost dead and without sensation."24

This brings us to considerations of discrimination. For many, it seems logical to assume that preserving disability by allowing disabled children to be born for the sake of diversity is an abhorrent conclusion. How-

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<sup>&</sup>lt;sup>20</sup> John Hyde Evans, *Playing God: Human Genetic Engineering and the Rationalization of the Public Bioethical Debate (Chicago: The University of Chicago Press, 2002), 184–185. Evans goes on to say, "Using argument that maximize beneficence, the scientists would experience little opposition from within the bioethics/science jurisdiction."* 

<sup>&</sup>lt;sup>21</sup> Rosemarie Garland-Thomson, "The case for conserving disability," *Journal of Bioethical Inquiry* 9, no. 3 (2012) as found in Robert Sparrow, "Imposing Genetic Diversity," The American Journal of Bioethics 15, no. 6 (2015): 3.

<sup>&</sup>lt;sup>22</sup> Sparrow, Imposing Genetic Diversity, 3.

<sup>&</sup>lt;sup>23</sup>Sparrow gives three cases "against" imposing diversity. First, one might simply deny that diversity in and of itself has any value at all. Second, even if we were to allow diversity, we may be reluctant to act so as to secure such diversity at the cost of some individuals having lower expected welfare than others. Third, to argue that because diversity will still exist in both of these scenarios as a result of various contingencies across the course of the human life span, there is no need to impose it. Sparrow, *Imposing Genetic Diversity*, 6.

<sup>&</sup>lt;sup>24</sup> Martin Luther. Luther's Works. American ed. Edited by Jaroslav Pelikan. Vol. 1, Lectures on Genesis: Chapters 1-5 (Saint Louis: Concordia Publishing House, 1958): 62.

For many of those who comprise this community, being different does not mean being disabled.

ever, there are some disabled communities that take offense at efforts to eliminate their disabilities through genetic selection. Sara Weinberger and Dov Greenbaum point out that the deaf community and the autistic community are particularly affected by this type of discrimination.<sup>25</sup> They have felt threatened by the assumption that they are considered "disabled" and have a condition that needs to be eliminated or corrected. For many of those who comprise this community, being different does not mean being disabled. This creates a problem or a "moving target" of what is considered a disability and what is not. Weinberger and Greenbaum point out:

Part of the problem is the inherently moving target: Whenever we select against a trait through assisted reproductive technologies, what ought to be the litmus test deciding which genetic disorders are "bad enough" to select against and what genetic conditions ought to be positively selected for? Is an objective set of criteria even possible?<sup>26</sup>

When we do try to remove genetic diseases from humanity, we begin to quickly slide down the "slippery slope" of discrimination and eugenics, where we will surely discover an ever-increasing set of genetic traits that will henceforth be rejected. Yet, it would seem impossible to devise a set norm of objective genetic code that would be universally accepted as objectionable.

The question posed to the members of Christ Lutheran Church regarding the use of genetic editing for better health in pre-born children resulted in a small majority (51%) of those surveyed saying they probably or most definitely would take advantage of it (Figure 3). If the procedure was safe, effective, and inexpensive, it makes sense that parents would want to do what is best for their children by giving them every health advantage possible. After further instruction on how germline genetic modifications are accomplished (through the harvesting of eggs and sperm in a laboratory and then implanted into the mother's womb), many of those who answered in the affirmative expressed greater reservations. If mentioned that if this procedure could be done in utero, they indicated a greater likelihood of using it. Yet, others still had reservations<sup>27</sup> since the modifications to the germline genome will subsequently affect every future generation after that child. It was thought by some that this would impose characteristics that were not a part of God's original plan for that person (even if it was for a health related issue) who could not give consent for such changes.

## **Ethical Issues of Somatic Cell Enhancement**

Beyond reversing disease or disability within the human genome is the idea of using this genetic editing to enhance physical, mental, or even emotional characteristics. We might imagine a world where rogue scientists are injecting themselves

<sup>&</sup>lt;sup>25</sup> Sara Weinberger and Dov Greenbaum "Genetic Technology to Prevent Disabilities: How Popular Culture Informs Our Understanding of the Use of Genetics to Define and Prevent Undesirable Traits," *The American Journal of Bioethics* 15, no. 6 (2015): 32.

<sup>&</sup>lt;sup>26</sup> Weinberger and Greenbaum, Genetic Technology to Prevent Disabilities, 33.

 $<sup>^{27}\,\</sup>text{Sixteen}$  percent (7) said they would not use genetic editing for their children while 33% (14) said they might use it. See Figure 3 in Appendix II.

and others with CRISPR programed to create giant biceps or a higher IQ. Identifying a moral error within this is more difficult, since improving self through somatic enhancements have the potential to hurt only the person receiving the treatment. So, what are the moral issues surrounding the use of genetic editing for somatic cell enhancement?

With enhancement, we begin with our own image and then we project our idea of the ideal human image onto God: we express to God that the image he created, that is the human self, begins first with us and not with him. If indeed it begins with us and not God, "then we set the parameters on our own self-image apart from what God has made us to be."28 We are blessed to be created in God's own image and this is not to be taken flippantly. Being human means that we have a conscience, we have reason, a capacity to communicate and the ability to worship the one true God from whom we are made. To be created in God's image means to be created in relationship to him in a unique way. This, in turn, is God's unique work to create us in the way he so designed.29 The temptation, and subsequent moral crux, is the implication that something is missing in God's creation and that deficiency needs to be corrected. Richard Eyer says:

Even in the fallen world, in which it is evident that what God intends is not always what is, there is something wrong with our trying to remedy the situation. Remedies are given by God and not everything man is capable of doing is necessarily a remedy, regardless of how

it appears to us at the moment... The moral error is trying to remedy what is wrong with us through genetic enhancement in that we tend to think that enhancement can meet those needs that only God can meet spiritually.<sup>30</sup>

Somatic cell genetic editing for enhancement apart from therapeutic reasons finds its roots in the vain pursuit of physical idealism by ultimately setting man's will for self-fulfillment before God's creative will. While this may only affect the one receiving this treatment, it does indeed hurt the spiritual self as such practices put the self in contrast to God's design. The ethical failing here is the sin against the first commandment as man desires to put himself in the place of God by altering what God has made.

A majority of the members surveyed during Bible class (25 of 43 members, or 58%) agree that they would not consider genetic editing for better physical appearance (Figure 4). Pervasive among them, before any discussion on the issue could commence, was the general idea that this notion of genetic editing took things too far. They feared that this activity could clearly be defined as, "putting man in the place of God." After further dialog on this matter, many mentioned that the discussion confirmed their initial feelings about the topic. One person mentioned that small enhancements to the human genome do not seem to be any more of an ethical problem than if someone were to put on makeup or color one's hair. However, the irreversibility of modifying the genome makes this a different issue and implies that the person is not satisfied with who God has made them to be.

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<sup>&</sup>lt;sup>28</sup> Richard Eyer, *Holy People, Holy Lives: Law and Gospel in Bioethics* (St. Louis: Concordia, 2000), 134.

<sup>&</sup>lt;sup>29</sup> AE 1:62.

<sup>30</sup> Eyer, Holy People, Holy Lives, 133.

## **Ethical Issues of Germline Cell Enhancement**

Choosing a child's hair color, height, or even the level of intelligence sounds like something right out of a science-fiction screenplay instead of a viable genetic engineering option for future patients. However, some scientists say we are not far off from this fantasy becoming reality. With it comes a host of ethical dilemmas, including two that we will touch on here: the child's autonomous rights (ability to give consent) and the idea of perfectionism.

With regard to child consent, an unborn child has no say in whether he or she wishes to be the subject of genetic enhancements, even if others have in mind every good intention. Because of the extreme nature of this kind of intervention, we cannot presume to know whether or not the characteristics chosen by the parents are in line with the child's desires or interests. Although some will make the argument that parents are given the right to choose their child's school, extracurricular activities, and make other decisions for the child's well-being, there is a stark contrast: these decisions are reversible if they are not in the child's best interest.31 Along the same lines, we permit parents to intervene on their child's behalf based on the presumption that they are doing so for the child's own good. However, with genetic enhancement, it is entirely possible that the enhancements are made to suit the desires of the parent, not for the sake of the child. These questions are not easily answered, because the entire truth may not be apparent to anyone.

With regard to perfectionism, germline enhancement allows the possibility of creating the perfect child, both without disease and with every advantage of physical and mental strength. Edwin Etieyibo calls this danger the "unfair advantage argument."32 He suggests that access to genetic enhancement technologies will depend exclusively on the ability to pay for such services, and thus creates unjust outcomes such as genetic caste systems, as well as the exacerbation and perpetuation of existing socio-economic inequalities. Paul Johnson goes so far as to suggest that, if the affluent produce genetically enhanced children, the likelihood of them marrying outside of their own social economic and genetic group will vanish. This will produce even deeper antagonisms as it leads to two radically different groups of human beings - a master race and a servile race.33

The counter-argument is that, given the prima facie benefits to genetic enhancement technologies, why object to it? If it were possible to become faster, stronger, and more intelligent - if we could be engineered to accomplish tasks more efficiently - why not seek out these helpful alterations? Even conceding these points, the end result does not justify the injustice that is sure to follow. If access to enhancement procedures is determined solely by the ability to pay for them, then outcomes will exacerbate and perpetuate through the disadvantaged community, creating social disparities on

<sup>&</sup>lt;sup>31</sup> Smolenski, *CRISPR/Cas9* and *Germline Modification*, 36.

<sup>&</sup>lt;sup>32</sup> Edwin Etieyibo, "Genetic Enhancement, Social Justice, and Welfare-Oriented Patterns of Distribution," *Bioethics 26, no. 6* (2012): 296-297.

<sup>&</sup>lt;sup>33</sup> Paul Johnson, Spectator, March 6, 1999 as found in Louis I. Gerdes, ed., Genetic Engineering: Opposing Viewpoints (Farmington Hills: Greenhaven Press, 2004), 87.

a severe level. In reality it is a kinder, gentler form of eugenics because there appears to be no violence or coercion (as during the days of Nazi Germany), nor does it specifically indicate that it is targeting one group over another. Nevertheless, the consequence of valuing some persons over others is inevitable.

Beyond social-justice issues are the deeper moral/Christian issues against using germline enhancement technologies. For starters, there is no Christian essentialist understanding of the body.34 Humans are not created with pristine bodies impervious to disease or injury; therefore, perfectionism by genetic enhancement should not be our primary endeavor. Secondly, perfectionism cannot be attained: humans can be improved but never perfected. Third, the institution of marriage, God's created order, and God's love for every individual of every ability, is unseated by sinners in favor of the procreation of perfected children for the sake of satisfied parents and society. Correcting a tainted genetic code in a child so that he or she does not carry the gene for cystic fibrosis is one thing. However, changing physical attributes to create a higher order of humans explicitly falls in the category of playing God. Lastly, we cannot obtain perfection because sin will always infest the human condition. Even our best intentions are distorted by sin and often create a sin where we see no fault. Man's own self-justifications and rationalizations cloud judgments and distort perceptions. Since sinning more is inevitable, and since moral uncertainty leads to a troubled conscience and damage to faith, such modifications are to be avoided altogether.<sup>35</sup>

The members surveyed at Christ Lutheran Church found significant moral objection to genetically modifying pre-born children for the purposes of physical enhancement (Figure 5). Sixty-seven percent (29) said they would not make enhancements to their children while 28% (12) said they "might." No one said they would definitely modify their children. After addressing the Bible class by pointing out the moral and theological objections of germline genetic enhancement, most, if not all, the members in the Bible class felt as if it would be wrong to do so.

### Theological and Pastoral Considerations

The primary battleground for Christians going forward rests on the matter of ultimate control. Will creation live within God's divine narrative or will people succumb to the myth of the autonomous life? Insights made by C.S. Lewis in *The Abolition of Man* are quite telling and pertinent to the issue at hand:

From this point of view the conquest of Nature appears in a new light. We reduce things to mere Nature in order that we may 'conquer' them. . . As long as this process stops short of the final stage we may well hold that the gain outweighs the loss. But as soon as we take the final step of reducing our own species to the level of mere Nature, the whole process is stultified, for this time the being

Will creation live within God's divine narrative or will people succumb to the myth of the autonomous life?

<sup>&</sup>lt;sup>34</sup> Essentialism is here defined as the belief that humans have a set number of characteristics that make them who they are. Science endeavors to discover the biological traits of humans or the philosophical expressions of what makes a person who they are.

<sup>&</sup>lt;sup>35</sup> These four moral claims are loosely based on Brent Waters, *Christian Ethics and Human Germline Genetic Modification*, 176–180.

who stood to gain and the being who has been sacrificed are one and the same. This is one of the many instances where to carry a principle to what seems its logical conclusion produces absurdity. It is like the famous Irishman who found that a certain kind of stove reduced his fuel bill by half and thence concluded that two stoves of the same kind would enable him to warm his house with no fuel at all.<sup>36</sup>

If man is able to reduce life to mere nature instead of viewing man as one who is created in the image of God, there becomes no limit to what man is able to do to the self. If the aim of gene therapy is the alleviation of human illness, then it has the potential to elevate the image of God. Man is called by God to be good stewards of the human body, viewing life as a divine gift that should be treasured. However, attempting to create some new creature with superlative powers would be playing God, since it would stem from human conceit regarding the unlimited nature of human resources, including the ability to create and control in far-reaching ways.37 We might call this the "Tower of Babel" effect where mankind decides to exploit power and achievement entirely apart from God. Man threatens to seize the place of God as the creator and designer in hopes of improving what God could not get right, or what man in the past had done so wrong. Thus, "making a name for ourselves" in this world would be to let loose the "Tower of As Christians, we acknowledge that we have limited capacities and cannot grasp the entirety of how we are fearfully and wonderfully made. We make it clear that we are God's creation justified by Christ, and this justification is what restores the image of God within us. "We are a new creation re-created in His image."39 The theological problem with genetic engineering is its attempt to fulfill the human potential by changing certain God-determined characteristics. To go a step further, man attempts to attain or "recreate" his own image through his own redesign, rather than relying on the real fulfillment found in God's redesigning our relationship with him through the work of Christ.

For the most part, Bible class discussion with the members at Christ Lutheran Church centered on what the Lord has made us to be as a community of believers in contrast to mankind's desire to become autonomous. The class realized that the primary dogma of genetic engineering is geared toward a "freedom from" pain, suffering, and dependence on God and others instead of a "freedom for" the opportunity to serve and be served in times of need, reliance on God for strength in the midst of suffering, and spiritual growth through daily trials that may include our own illnesses or the service to others who are ill.40 The common refrain targeted by the class was the

Babel" effect into the uninhibited use of the technology of today.<sup>38</sup>

<sup>&</sup>lt;sup>36</sup> C. S. Lewis, The Abolition of Man: How Education Develops Man's Sense of Morality (San Francisco: HarperCollins, 2001), 83.

<sup>&</sup>lt;sup>37</sup> Jones, Valuing People, 148.

<sup>&</sup>lt;sup>38</sup> See also, Russell Disilvestro, "Three Christian Arguments Against Germline Engineering," *Christian Bioethics* 18, no. 2 (2012): 205.

<sup>&</sup>lt;sup>39</sup> Eyer, Holy People, Holy Lives, 136.

<sup>&</sup>lt;sup>40</sup> See Jean-Claude Larchet, The Theology of Illness (Crestwood: St. Vladimir's Seminary Press, 2002), 64ff.

Christian's vocational calling to be a receiver and a provider in the midst of trouble. Since trouble and suffering can never be totally avoided the class understood how the continual quest to live the autonomous life will eventually limit how God's people are given to serve and be served by others and thereby reduce the need to rely on God's providential care.

God calls man to care for the neighbor and thus calls him to heal his neighbor. The healing arts are a gift established by God who has given man the objective of being good stewards of creation, preserving, mending, and transforming the world in ways that are in accordance with God's purposes. Therefore, the theological and moral problem we must address is not so much the concept of editing defective genes in order to cure disease, but rather the intent and motivation behind the practice. Hence, this paper has attempted to clarify the ethical and biological distinctions between therapeutic and enhancement uses of genetic editing. Identifying at what point one moves from therapy to enhancement can be vexing and difficult to determine; however, this does not mean that all forms of therapeutic genetic editing should be abandoned. The misuse of it does not preclude its beneficial and appropriate use. Again, matters that concern intent require careful consideration in order to discover the true motive behind the use of genetic editing.

The world tends to view God's creation through a gnostic lens wherein the human body is merely a tainted disposable shell that does not truly articulate who we really are. An important theological theme to consider, therefore, is the doctrine of the Incarnation: the Word made flesh af-

firms the goodness of the embodied life. "Humans are created by God as bodied beings, not souls trapped in bodies."41 The Word made flesh for us affirms God's people as body and soul together. Within the whole of our very being we are both afflicted with sin and declared righteous at the same time. We are both able and disabled, whole and broken, strong and weak, vibrant and dying. Our condition changes over time for either the good or the bad. The image of God does not fade away as our bodies get weaker. It does not entail a denial of this finite body as time moves on and parts wear out. Our Savior comes as we are in order to suffer the same mortal fate as all human creatures. Most importantly, he comes to identify with our "fallen-ness" by taking upon himself our broken lives in order to give us regenerated bodies on the last day.

Even so, mankind would much rather ascend to the level of God's flawless perfection than identify with a lowly Nazarene. It is assumed that rising to new heights means better lives, better children, and the greater potential of abolishing misery and distress for generations to come. However, history has shown that the eugenic impulse to eradicate suffering associated with disability has produced grave consequences and must be avoided at all cost. This dare not get in the way of our welcoming children unconditionally as God's gift with respect to their intrinsic, non-instrumental value no matter what they have or how they are born.42 The danger is that such the doctrine of the Incarnation: the Word made flesh affirms the goodness of the embodied life.

<sup>&</sup>lt;sup>41</sup> Waters, Christian Ethics and Germline Genetic Modification, 172.

<sup>&</sup>lt;sup>42</sup> Neil Messer, "Introduction: Theological Anthropology and the Ethics of Human Germ Line Genetic Modification," *Christian Bioethics* 18, no. 2 (2012): 119.

eugenic notions will cause humanity to view those disabled as less than what God created them to be — his very own children wrapped in the identity of Christ gained at baptism. This cautionary pastoral matter must be addressed within the body of saints by grounding God's people in his explicit acceptance of all sinners who embody within themselves all kinds of disease and disability.

The rightful purpose of genetic engineering is to serve the needs of humanity. It is undeniable that this is the intent of many of those who continue to pursue the new hope that genetic editing tools, such as CRIS-PR, hope to accomplish. Such deeds are moved by benevolent concern for the reprieve of future suffering. This is indeed admirable. But the issue still remains: just because man has been given the freedom and the ability to make changes to the human genome does not mean that he always should. Meilaender eloquently concludes by saying, "the most truly human and humane exercise of our freedom may be the courage that says no when asked to make humankind itself our patient."43

With the advent of new technologies in genetic editing gaining momentum and acceptance, Christians need to recognize mankind's place within the scientific quest to expand the limits of creation. From the beginning, we must reckon with our own limits of knowledge and control over the future and have an attitude of contentment in light of what we are not given to change. We must be more disposed to seek wisdom over power and to understand that what we might seek to change may not always be for the sake of the good we hope to obtain. Good is not always at our disposal and change is not always good. Care for the whole person yields to the will of God and seeks not to become nature's master. God must remain God — at the helm of all creation. His job is not ours to take.

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#### Appendix I

- 1. How much do you know about genetic editing?
- A. I've never heard anything about it.
- B. I've heard of it but don't know anything about it.
- C. I know a little about what it is and how it works.
- D. I have learned a lot about genetic editing and think I have a pretty good handle on it.
- 2. If genetic editing were safe, effective, inexpensive and would help improve your overall health and lifestyle would you make use of it?
- A. No
- B. It's possible
- C. I probably would
- D. Most definitely
- 3. If genetic editing were safe, effective, inexpensive, and would help ensure that your pre-born child would not be born with a dis-

<sup>&</sup>lt;sup>43</sup> Meilaender, Bioethics, 44.

ability they "may" come to have, would you make use of it for your child?

- A. No
- B. It's possible
- C. I probably would
- D. Most definitely
- 4. If genetic editing were safe, effective, inexpensive, and could change your physical appearance to give you the features or characteristics you want, would you make use of it?
- A. No
- B. It's possible
- C. I probably would
- D. Most definitely
- 5. If genetic editing were safe, effective, inexpensive, and could change your pre-born child's physical appearance and give your child the features or characteristics you want for your child, would you make use of it?
- A. No
- B. It's possible
- C. I probably would
- D. Most definitely

### Appendix II

Figure 1

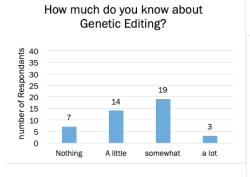


Figure 2

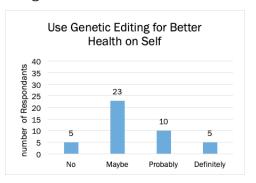


Figure 3

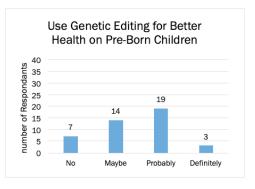


Figure 4

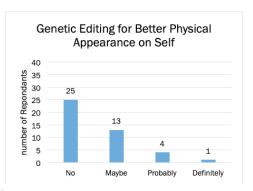
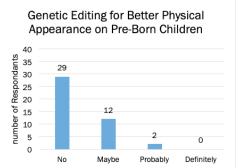


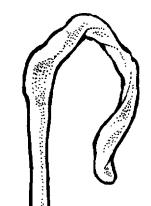
Figure 5



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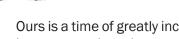
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### Reflection



Ours is a time of greatly increased opportunity and learning, especially in understanding our genetic code created by our Lord on day six. There are, of course, ditches on both sides of this new road: thoughtlessly rejecting any possible way to help those with serious illness by rejecting all genetic inquiry or to misuse our unborn brothers and sisters in a selfish attempt to save ourselves.

Pastor Tyler Arnold doesn't just skip a rock across the surface of the issues of genetic engineering. He makes careful and helpful distinctions that help faithful Christians intentionally consider what is wise. He has introduced us to CRISPR and its implications on somatic and germline cell editing. He has called us to thoughtfully contemplate the ethical challenges of genetic editing on somatic and germ cells. Best of all, Pastor Arnold helps seelsorgers to see the theological and pastoral concerns involved in genetic engineering. We dare not ignore these issues nor miss the powerful idolatries and misbeliefs that "lead us into despair, and other great shame and vice."

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Gracious Father, who first saw our unformed substance, we praise you for your creativity and wisdom in designing us and your mercy in giving us life, and for Jesus' work of healing — a promise of what the resurrection entails for all in Christ. Guard us from using others for our gain or seeking to save ourselves; bless those who work to relieve unhealthy bodies and give them wisdom and compassion; and bring us to the fullness of your eternal life; through Jesus Christ, your Son, our Lord, who lives and reigns with you and the Holy Spirit, one God, now and forever. Amen.

Pastor David C. Fleming