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## A CLEANER, CRISPR CONSTITUTION: GERMLINE EDITING AND FUNDAMENTAL RIGHTS

Andrew Cunningham\*

### INTRODUCTION

On August 2, 2017, genetic engineering once again burst into the world. On that date, a team of international researchers published their latest experiment.<sup>1</sup> These researchers used CRISPR/Cas9, the newest and most controversial genetic engineering technology, to edit a portion of a human embryo.<sup>2</sup> They succeeded in removing a genetic heart disease, known as hypertrophic cardiomyopathy, from the embryo's DNA.<sup>3</sup> Not only was this the first time researchers created a genetically modified embryo in the United States, it was the first time researchers successfully edited the DNA of an embryo, ever.<sup>4</sup> The experiment had groundbreaking consequences. This breakthrough sheds light not only on a future of cheap and safe genetic engineering, but also a future that morphs and modifies our conception of humanity. Even before CRISPR/Cas9, scientists and public figures warned against allowing such technology in fear of dystopia and the advent of "designer babies."<sup>5</sup> CRISPR/Cas9 has made that prospect a foreseeable reality.

CRISPR/Cas9 capabilities in gene editing deserve a constitutional conversation. Because of the novel nature of this technology, scholarship concerning the legal implications and constitutional dimensions of gene editing is scarce.<sup>6</sup> Now that the technology is at the doorstep of the United States, courts and legal scholars should

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<sup>1</sup> Pam Belluck, *In Breakthrough, Scientists Edit a Dangerous Mutation From Genes in Human Embryos*, N.Y. TIMES (Aug. 2, 2017), <https://nyti.ms/2hn29ey>.

<sup>2</sup> *Id.*

<sup>3</sup> *Id.*

<sup>4</sup> *See id.*

<sup>5</sup> Tia Ghose, *Children to Order: The Ethics of 'Designer Babies'*, LIVE SCIENCE (Mar. 13, 2014, 2:00 PM), <https://www.livescience.com/44087-designer-babies-ethics.html> [<https://perma.cc/P5EU-DTCZ>].

<sup>6</sup> John Attanasio discussed the constitutional dimensions of genetic engineering in general before CRISPR/Cas9 made it a practical reality. *See generally* John B. Attanasio, *The Constitutionality of Regulating Human Genetic Engineering: Where Procreative Liberty and Equal Opportunity Collide*, 53 U. CHI. L. REV. 1274 (1986) (surveying various aspects of constitutional law, including the right to privacy, as applied to genetic engineering). For a more general discussion tailored to CRISPR/Cas9, see Teddy Ellison, *Why Genetics Is CRISPR Than It Used to Be: Helping the Novice Understand Germ Line Modification and Its Serious Implications*, 26 S. CAL. INTERDISC. L.J. 595 (2017).

expand the dialogue. We should take more seriously the arguments that were once resigned to science fiction novels. Although it may be some years before the safety and reliability issues are seamed over, an *ex ante* discussion is invaluable for such controversial treatments. There is good reason to believe the federal or state governments would—at least initially—prohibit CRISPR/Cas9 germline modification. As of 2015, twenty-nine countries, including Britain, Canada, Sweden, France, and Australia, have banned gene editing in embryos.<sup>7</sup> So far, the U.S. state and federal governments have not explicitly addressed the issue.<sup>8</sup> A revolutionary treatment, capable of removing genetic diseases,<sup>9</sup> could be just years away from mainstream incubation.<sup>10</sup> So, cue the legal inquiries: Does the right to privacy include the editing of offspring DNA? Does it violate the future child's autonomy? Does the individual at least retain a substantive due process right to access medicine from private sources?

This Note argues that the individual does not retain a fundamental right in using CRISPR/Cas9 germline editing to remove hereditary disease. Although the Supreme Court might recognize some limited “liberty interest” in the practice, germline editing is, regardless of this, subject to legislative regulation. We can foresee, one day, an individual claiming a right to remove a genetic disease from her child via CRISPR/Cas9. If she already enjoys the right to terminate the pregnancy, why should she not have the same right in choosing its genetic disposition? The Court would have several avenues from which to analyze her claim: the right to privacy, broader rights to individual or minor autonomy, the right to access medicine, self-definition, etc. This Note will analyze the strengths and weaknesses of those and similar claims through various constitutional doctrines. Because gene editing through CRISPR/Cas9 creates an unfamiliar factual background, the Court might use its precedent more as reflections of values rather than concrete rules. Ultimately, the Court would find the state's interest in medical regulation worthy of protection against the individual's claim to privacy. Citing the state's interest in protecting public health and welfare, the Court would uphold a legislative prohibition on the practice. Concerns with CRISPR/Cas9 do not stop at safety issues. A myriad of ethical issues engulf the procedure, including fears of eugenics and entrenching social disparities. Those concerns, the Court would hold, are sufficient to trump an individual's autonomy interest in using CRISPR/Cas9. Moreover, legislatures are in the best position to arbitrate over such unresolved social and ethical problems.

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<sup>7</sup> Heidi Ledford, *Where in the World Could the First CRISPR Baby Be Born?*, NATURE (Oct. 13, 2015) [hereinafter Ledford, *Where in the World*], <https://www.nature.com/news/where-in-the-world-could-the-first-crispr-baby-be-born-1.18542> [<https://perma.cc/78WW-7YHP>].

<sup>8</sup> *See id.*

<sup>9</sup> *See* Liqun Cai et al., *CRISPR-Mediated Genome Editing and Human Diseases*, 3 GENES & DISEASES 244, 247 (2016). Using CRISPR/Cas9 editing, scientists prevented an HIV virus from spreading within infected cells. *See* Youdiil Ophinni et al., *CRISPR/Cas9 System Targeting Regulatory Genes of HIV-1 Inhibits Viral Replication in Infected T-Cell Cultures*, 8 SCI. REPS. 7784, 7784–85 (2018).

<sup>10</sup> *See* Cai et al., *supra* note 9, at 249.

Part I details how CRISPR/Cas9 editing works and highlights the difference between somatic and germline cell edits. The following sections explain how CRISPR/Cas9 is superior to other gene editing techniques and how it effortlessly proliferates within the medical market. It then discusses the predominate concerns with the technology, including safety, exacerbating inequalities, and the fear of positive eugenics.

Part II asks whether the constitutional right to privacy includes the right to edit an embryo's germline. The first section summarizes the right and concludes that the Court must interpret CRISPR/Cas9 procedures through more specific elements within the right. The next section applies the "burden" argument in abortion jurisprudence to removing genetic defects from an embryo. The third section questions whether there is a more inclusive right to trait selection through abortion and, if so, if that right extends to trait selection through CRISPR/Cas9. The last section covers the strength of a minor's right to bodily autonomy and whether genetic engineering violates this right.

Finally, Part III considers whether the individual enjoys a right to access medical treatments from private sources. The individual, after all, could make a prima facie case that a prohibition on CRISPR/Cas9 is unreasonable and arbitrary and that she has a constitutionally protected choice in private medical treatment. The first section explains how the "medical necessity" doctrine ultimately precludes gene editing treatments. The next section reviews the Court's history of deferring to the state interest in protecting public health. Because there are so many public health concerns with CRISPR/Cas9, the Court would defer to the legislature and uphold any regulation. The last section argues that this deference approach conveniently avoids the problem of answering whether there is a right to create disability.

## I. THE CRISPR REVOLUTION

### A. *What Is CRISPR/Cas9?*

In 2007, scientist Francisco Mojica first discovered Clustered Regularly Interspaced Short Palindromic Repeats,<sup>11</sup> making a crisp acronym. Found in immune system bacteria, CRISPR is the bacteria's mechanism for warding off viruses.<sup>12</sup> When a virus infects the bacteria, CRISPR—an internal component—keeps a piece of genetic code from that virus.<sup>13</sup> Now that the bacteria can recognize the virus, its immune system can more quickly attack the virus if it reappears.<sup>14</sup> Essential to the process, CRISPR produces an enzyme called Cas9, which can bind and cut strands of DNA from a CRISPR

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<sup>11</sup> *Questions and Answers About CRISPR*, BROAD INST., <https://www.broadinstitute.org/what-broad/areas-focus/project-spotlight/questions-and-answers-about-crispr> [<https://perma.cc/ZBP6-SLD5>].

<sup>12</sup> *Id.*

<sup>13</sup> *See id.*

<sup>14</sup> *Id.*

sequence, called a “spacer” sequence.”<sup>15</sup> Scientists can modify the Cas9 enzyme to snip pieces of the target cell’s DNA, allowing them to study gene function.<sup>16</sup> The process operates much like a “cut and paste” technique.<sup>17</sup> After extracting the CRISPR sequence with Cas9, scientists can then “guide” the CRISPR sequence to replace specific sequences in the DNA.<sup>18</sup> Through CRISPR/Cas9, scientists can remove genetic disorders by replacing the abnormal chromosome with an unaffected sequence.<sup>19</sup>

One of the most controversial uses of CRISPR/Cas9 is for germline editing.<sup>20</sup> There are generally two kinds of therapy involving gene editing: somatic and germline cell therapy.<sup>21</sup> In somatic cell therapy, the modifications do not pass to future generations.<sup>22</sup> The affected cells are confined to the individual.<sup>23</sup> In germline editing, the offspring inherits every change, and those genetic changes are passed on to future generations.<sup>24</sup> This kind of genetic engineering is only feasible at the embryonic stage.<sup>25</sup> Germline editing is much more controversial than somatic cell therapy for several reasons. First, many more individuals are affected.<sup>26</sup> Unless the children change their own genetic makeup, the changes from the initial CRISPR/Cas9 germline edit would be present in every single individual in that family line.<sup>27</sup> As a result, many more are at risk of mutational side effects.<sup>28</sup> Second, because germline editing can affect traits that are only in DNA, this kind of treatment creates greater risks of “designer babies.”<sup>29</sup> The phrase implies a callous disregard for the sanctity of birth, equating newborns with fashion accessories.

One of the most groundbreaking parts of CRISPR/Cas9 is its low cost and remarkable accuracy.<sup>30</sup> Prior to this technology, scientists conducted DNA editing through

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<sup>15</sup> *Id.*

<sup>16</sup> *See id.*

<sup>17</sup> Jon Entine, *Ethical and Regulatory Reflections on CRISPR Gene Editing Revolution*, GENETIC LITERACY PROJECT (June 26, 2015), <https://www.geneticliteracyproject.org/2015/06/25/ethical-and-regulatory-reflections-on-crispr-gene-editing-revolution> [<https://perma.cc/H298-UNTY>].

<sup>18</sup> *See* Sarah Ashley Barnett, Comment, *Regulating Human Germline Modification in Light of CRISPR*, 51 U. RICH. L. REV. 553, 558 (2017).

<sup>19</sup> *See, e.g.,* A.F. Mentis, *Epigenomic Engineering for Down Syndrome*, 71 NEUROSCIENCE & BIOBEHAVIORAL REVS. 323, 325 (2016).

<sup>20</sup> Barnett, *supra* note 18, at 553.

<sup>21</sup> *Id.*

<sup>22</sup> Sarah Polcz & Anna Lewis, *CRISPR-Cas9 and the Non-Germline Non-Controversy*, 3 J.L. & BIOSCIENCES 413, 414 (2016), <https://academic.oup.com/jlb/article/3/2/413/1751234> [<https://perma.cc/DA5K-M7C3>].

<sup>23</sup> *Id.*

<sup>24</sup> Barnett, *supra* note 18, at 556.

<sup>25</sup> *Id.* at 555.

<sup>26</sup> *See id.* at 556.

<sup>27</sup> *Id.*

<sup>28</sup> *See id.* at 558.

<sup>29</sup> *See id.* at 555.

<sup>30</sup> *Id.* at 565–66.

techniques known as zinc finger nucleases (ZFNs) and transcriptional activator–like effector nucleases (TALENs).<sup>31</sup> However, these technologies were deficient in a number of ways. They could only edit one genome sequence at a time, whereas CRISPR/Cas9 can edit many at once.<sup>32</sup> They took researchers months to perform, and even then scientists could not guarantee complete accuracy.<sup>33</sup> CRISPR/Cas9 takes only several weeks.<sup>34</sup> So far, CRISPR/Cas9 has been the source of many experiments that were “previously difficult or impossible to conduct.”<sup>35</sup> In addition, and more importantly, CRISPR/Cas9 reduces the cost associated with DNA manipulation to an unprecedented degree. Where ZFNs and TALENs cost anywhere from \$500 to \$5,000, CRISPR/Cas9 is available at around \$30 in most cases.<sup>36</sup> One crafty man made headlines when he began producing CRISPR kits in his garage.<sup>37</sup> The improved accuracy and reduced cost has enormous social implications.<sup>38</sup> Genetic engineering is no longer a pipe dream.

### B. Alternatives to CRISPR/Cas9

The advent of assisted reproduction technologies (ARTs) in the late nineteenth and early twentieth century revolutionized procreative decision-making.<sup>39</sup> In vitro fertilization (IVF) procedures requires a physician to remove several mature eggs from the woman’s ovaries and fertilizes them in a laboratory.<sup>40</sup> The physician then implants the eggs back in the uterus, a process which takes about two weeks.<sup>41</sup> Since then, IVF has become “the most effective form”<sup>42</sup> of ART. Another alternative procedure is preimplantation genetic diagnosis (PGD).<sup>43</sup> Once a physician extracts the mature eggs in an IVF procedure—but before he transplants them back in the uterus—the physician can search each fertilized egg for genetic defects.<sup>44</sup> PGD

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<sup>31</sup> *Id.* at 562.

<sup>32</sup> *Id.* at 563.

<sup>33</sup> *Id.*

<sup>34</sup> *Id.* at 564.

<sup>35</sup> Jennifer Doudna, *Embryo Editing Needs Scrutiny*, 528 NATURE 6, 6 (2015).

<sup>36</sup> Nathan Guo, *CRISPR—The Future of Synthetic Biology*, LUX CAP. (July 7, 2015), <http://www.luxcapital.com/news/crispr/> [<https://perma.cc/7DR9-3WFB>].

<sup>37</sup> Sarah Zhang, *A Biohacker Regrets Publicly Injecting Himself With CRISPR*, ATLANTIC (Feb. 20, 2018), <https://www.theatlantic.com/science/archive/2018/02/biohacking-stunts-crispr/553511/> [<https://perma.cc/KK84-D7MU>].

<sup>38</sup> *See id.*

<sup>39</sup> *See* Remah Moustafa Kamel, *Assisted Reproductive Technology After the Birth of Louise Brown*, 14 J. REPROD. & INFERTILITY 96, 96 (2013).

<sup>40</sup> *In Vitro Fertilization (IVF)*, MAYO CLINIC, <https://www.mayoclinic.org/tests-procedures/in-vitro-fertilization/home/ovc-20206838> [<https://perma.cc/2KA5-9XHN>].

<sup>41</sup> *Id.*

<sup>42</sup> *Id.*

<sup>43</sup> *See* Barnett, *supra* note 18, at 556.

<sup>44</sup> *See id.*

affords the parent(s) a choice of which embryo to carry, a choice which enables discrimination based on traits.<sup>45</sup>

IVF and PGD are alternatives to CRISPR/Cas9 germline editing in removing disease.<sup>46</sup> But to say they are *viable* alternatives ignores the practical differences—namely, price and accessibility. It would be like saying liposuction is a viable alternative to weight loss pills. Liposuction may have less negative side effects, but the pills are much cheaper and available at the drug store down the street. IVF medications cost, on average, between \$3,000 and \$4,000.<sup>47</sup> PGD costs about \$3,500,<sup>48</sup> far out of reach for the average family income. It's not difficult to see why there is so little demand for such techniques, even where there is a substantial likelihood the embryo would carry a genetic defect. The practical impact of CRISPR/Cas9's low cost and ease of access should not be understated.

Another major difference between these procedures is embryo destruction. IVF and PGD involve the destruction of each unused embryo, while in CRISPR/Cas9 the single embryo survives (if desired by the parent).<sup>49</sup> Those who believe in a fetal right to life would presumably never choose IVF and PGD because the unselected embryos would not survive. But CRISPR/Cas9 does not evoke these same concerns because it edits only a single, surviving embryo.

### C. Concerns with CRISPR/Cas9

Genetic engineering is a moral quagmire. Literature discussing its social, economic, and legal implications only scratch the surface. CRISPR/Cas9 introduces *choice* in an area which was previously randomized. The idea that choice is an essential precondition to moral action has been part of philosophical debate since the days of Thomas Aquinas.<sup>50</sup> Although abortion and newer reproductive technologies allow parents to pick and choose potential children, never before has this choice been so readily accessible. The result is a surplus in bioethical opinions, statements, and recommendations about the practice.<sup>51</sup> The following subsections explore the myriad

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<sup>45</sup> *See id.*

<sup>46</sup> *See id.* at 556–58.

<sup>47</sup> *PGD and IVF Costs*, ADVANCED FERTILITY CTR OF CHI. (2017), <https://www.advancedfertility.com/pgd-costs.htm> [<https://perma.cc/RGF7-YWVJ>].

<sup>48</sup> *Id.*

<sup>49</sup> *See* Mike Antonucci, *Danger Ahead*, STANFORD MAG. (Nov/Dec 2015), <https://stanfordmag.org/contents/danger-ahead-14677> [<https://perma.cc/SN7N-JKQC>].

<sup>50</sup> *See* THOMAS AQUINAS, *SUMMA THEOLOGICA*, Pt. I–II, qq. 6–17 (William Benston, pub., Encyclopedia Britannica, ed.) (1941) (arguing choice is essential to self-determination).

<sup>51</sup> NAT'L ACAD. OF SCI., *HUMAN GENOME EDITING: SCIENCE, ETHICS, AND GOVERNANCE* (2017) (discussing the myriad of social and ethical issues surrounding genome editing in general). *See generally* Francis S. Collins, *Statement on NIH Funding of Research Using Gene-Editing Technologies in Human Embryos*, NAT'L INST. HEALTH (Apr. 28, 2015), <https://www.nih.gov/about-nih/who-we-are/nih-director/statements/statement-nih-funding-research-using>



of safety, social, and ethical issues concerning CRISPR/Cas9 and genome editing in general.

### I. Safety Issues

At this moment, safety is the most pressing concern with CRISPR/Cas9 technology. Unresolved safety issues are largely why scientists are so hesitant to begin clinical trials with human germline modification.<sup>52</sup> In 2015, gene-editing technology originally presented the problem of inaccurate editing and “off-target effects,” or unwanted genetic changes.<sup>53</sup> However, in the aforementioned 2017 CRISPR/Cas9 experiment, the reproduced cells contained one hundred percent of the original, modified gene with no off-target effects.<sup>54</sup> Although the threat of off-target effects will always be theoretically present, the most recent experiment shows significant progress in overcoming these safety hurdles.

Using CRISPR/Cas9 to change the human germline presents greater problems, however. Because the changes pass through multiple generations, there is no way to tell if unexpected side effects will appear in those subsequent generations.<sup>55</sup> This holds true even if there are no apparent problems in the generation that received the edits.<sup>56</sup> Clinical testing would have to span across at least a single generation to quell this fear: “Unless these effects are studied closely over time and against a diverse backdrop, the full medical implications of many genetic variants will not be fully understood until they present themselves in fully developed human subjects.”<sup>57</sup> Pending questions of safety prevent CRISPR/Cas9 from clinical testing, and it may take several years before scientists can smooth them over.

### 2. Aggravating Social Inequality and Stigma

Another prominent concern is CRISPR/Cas9’s potential to exacerbate social inequalities and reinforce stigmas. Of course, any reproductive procedure that affords

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-gene-editing-technologies-human-embryos [https://perma.cc/67K3-6NPS] (commenting that bioethicists at the NIH refuse to fund CRISPR/Cas9 given the enormity of safety and ethical issues and current lack of medical necessity); Eric S. Lander, *Brave New Genome*, 373 *NEW ENG. J. MED.* 5 (2015) (noting the director of the Broad Institute’s comments on both safety and ethical issues in germline editing from a scientific point of view).

<sup>52</sup> See Lander, *supra* note 51, at 6.

<sup>53</sup> Puping Liang et al., *CRISPR/Cas9-Mediated Gene Editing in Human Tripronuclear Zygotes*, 6 *PROTEIN & CELL* 363, 364 (2015).

<sup>54</sup> See Heidi Ledford, *CRISPR Fixes Disease Gene in Viable Human Embryos*, *NATURE* (Oct. 3, 2017), <http://www.nature.com/news/crispr-fixes-disease-gene-in-viable-human-em-zygotes-1.22382> [https://perma.cc/Q657-4489] [hereinafter Ledford, *CRISPR Fixes*].

<sup>55</sup> See Barnett, *supra* note 18, at 568.

<sup>56</sup> See Ledford, *CRISPR Fixes*, *supra* note 54.

<sup>57</sup> Barnett, *supra* note 18, at 568.



a choice in genetic outcomes, like IVF and PGD procedures, risks producing these effects.<sup>58</sup> But the affordability and accessibility of CRISPR/Cas9 make these effects much more foreseeable. One example of how this technology can aggravate social differences is CRISPR/Cas9's use in treating sickle cell anemia (SCA).<sup>59</sup> SCA disproportionately affects the African American population: about one in thirteen African American babies are born with the trait.<sup>60</sup> Those afflicted with SCA incur enormous medical costs.<sup>61</sup> Because a substantial portion of the African American population lives below the poverty line,<sup>62</sup> CRISPR/Cas9 technology raises fears that other diseases will be removed from the populace while SCA remains just as prevalent.<sup>63</sup>

Moreover, demarcating the line between disability and disease might reinforce stigmas about certain disabilities. The obvious example is Down Syndrome. A common mental disability, Down Syndrome is capable of treatment through genetic engineering.<sup>64</sup> Notwithstanding the potential for shorter life and an increased risk to contract other illnesses, those with Down Syndrome are disadvantaged only where society does not provide sufficient accommodation.<sup>65</sup> They suffer not from a disease but how society treats them. Many perceive rare conditions like Down Syndrome, blindness, or dwarfism as an element of diversity.<sup>66</sup> They are unique and conducive to an eclectic population. CRISPR/Cas9 thus has the potential to aggravate stigmas against those with such conditions by treating them as an unwanted disease.

### 3. Eugenics

Humans are no strangers to eugenics. Positive eugenics constitutes “the practice of *encouraging* the birth of children to parents having qualities considered desirable to the community.”<sup>67</sup> “Negative” eugenics, on the other hand, refers to limiting or

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<sup>58</sup> See generally PRESIDENT'S COUNCIL ON BIOETHICS, REPRODUCTION AND RESPONSIBILITY: THE REGULATION OF NEW BIOTECHNOLOGIES 96 (2004) (covering the many ethical issues associated with ARTs).

<sup>59</sup> *Data & Statistics on Sickle Cell Disease*, CTR. DISEASE CONTROL AND PREVENTION (Aug. 9, 2017), <https://www.cdc.gov/ncbddd/sicklecell/data.html> [<https://perma.cc/K55F-W42K>].

<sup>60</sup> *Id.*

<sup>61</sup> See *id.* In 2005, the average cost for children with sickle cell disease was \$11,702 for those on Medicaid and \$14,772 for workplace-covered insurance. *Id.*

<sup>62</sup> See Suzanne Macartney et al., *Poverty Rates for Selected Detailed Race and Hispanic Groups by State and Place: 2007–2011*, U.S. CENSUS BUREAU (Feb. 2013), <https://www2.census.gov/library/publications/2013/acs/acsbr11-17.pdf> [<https://perma.cc/2JQ9-2S7W>].

<sup>63</sup> See *id.*

<sup>64</sup> See Mentis, *supra* note 19, at 323.

<sup>65</sup> See *id.*

<sup>66</sup> See *id.* at 323–25; Lauren Oberheim, *Selective Hearing: Communication Barriers in the Court System for Deaf and Hard-of-Hearing Victims of Rape and Sexual Assault*, 25 WM. & MARY J. RACE, GENDER, AND SOCIAL JUSTICE 174–78 (2018).

<sup>67</sup> *Positive Eugenics*, ENGLISH OXFORD LIVING DICTIONARIES (emphasis added), [https://en.oxforddictionaries.com/definition/positive\\_eugenics](https://en.oxforddictionaries.com/definition/positive_eugenics) [<https://perma.cc/8SNE-GDH4>].

removing “defective” traits in the human gene pool.<sup>68</sup> Societies accomplish the latter through sterilization procedures, selecting certain individuals with undesirable traits and ensuring they cannot breed.<sup>69</sup> People have always favored traits that are conducive to social well-being like being tall, running faster, having a higher IQ, or possessing keener senses.<sup>70</sup> But now CRISPR/Cas9 introduces the element of choice in these qualities. Individuals can now assert their preference in qualities which were once randomized.<sup>71</sup> The choice, however, inevitably comes at the cost of favoring one trait over another. Some scholars have suggested such a system could create a “biological class system” tantamount to the United States’ previous race-based classifications.<sup>72</sup>

Negative eugenics makes up an ugly chapter in U.S. legal history. In one of its darkest hours, the Supreme Court in *Buck v. Bell*<sup>73</sup> upheld a Virginia statute that mandated sterilization for individuals with a history of “insanity, imbecility, etc.”<sup>74</sup> The Court’s language reflected society’s entrenched acceptance of this practice, in strong juxtaposition with our contemporary aversion to it: “It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind . . . [t]hree generations of imbeciles are enough.”<sup>75</sup> Although the Supreme Court effectively overturned *Buck* years later in *Skinner v. Oklahoma*,<sup>76</sup> CRISPR/Cas9’s flirtation with eugenics brings this debate back into the fold.

The lessons drawn from these cases are useful in analyzing CRISPR/Cas9 as a vehicle for positive eugenics. First, the *Buck v. Bell* time period highlights the need to make careful, *ex ante* policy considerations.<sup>77</sup> The prevailing social and ethical norms of the 1920s permitted a practice that, in contemporary times, is considered a gross infraction of an individual’s autonomy.<sup>78</sup> The Supreme Court is no stranger to incorporating policy concerns in their decisions, most notably through the use of socioeconomic evidence.<sup>79</sup> The Court thus cannot succumb to a social and ethical

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<sup>68</sup> *Negative Eugenics*, ENGLISH OXFORD LIVING DICTIONARIES, [https://en.oxforddictionaries.com/definition/negative\\_eugenics](https://en.oxforddictionaries.com/definition/negative_eugenics) [<https://perma.cc/Z2SZ-AHTS>].

<sup>69</sup> See Carolyn Brokowski et al., *Cutting Eugenics Out of CRISPR-Cas9*, 6 ETHICS BIOLOGY ENGINEERING & MED. 263, 270 (2015).

<sup>70</sup> See *id.*

<sup>71</sup> See *id.*

<sup>72</sup> *Id.*

<sup>73</sup> 274 U.S. 200 (1927).

<sup>74</sup> *Id.* at 206.

<sup>75</sup> *Id.* at 207 (internal citations omitted).

<sup>76</sup> 316 U.S. 535 (1942). The Court held the legislation permitting sterilization ran afoul of the Equal Protection Clause. *Id.* at 541. Although this left room for states to create constitutional sterilization laws that applied equally, states never created such laws. Widespread coverage of Nazi sterilization procedures the year before created sufficient unease with the procedure, a discomfort that is arguably just as prevalent today.

<sup>77</sup> See *Buck*, 274 U.S. at 200.

<sup>78</sup> See *id.*

<sup>79</sup> The most obvious example is how the Court used socioeconomic evidence to overturn

climate that favors private use of CRISPR/Cas9 without considering its potential for eugenics. For the Court—without considering the evolving nature of such norms—might realize its mistake after it is too late. After all, the Nazi’s eugenics program began with a campaign to first eliminate genetic disease from the populace.<sup>80</sup> Second, like with the inequality concerns, the threat of eugenics strengthens the state or federal government’s interest in banning human germline editing.<sup>81</sup> Fear of sliding into eugenics would supply the state with a convincing argument for prohibition.

## II. CRISPR/CAS9 AND PRIVACY INTERESTS

The Constitution provides each individual with a strong privacy interest against government interference.<sup>82</sup> Does this right encompass CRISPR/Cas9 germline editing? Proponents of genetic engineering often invoke the right to privacy to defend the practice.<sup>83</sup> They argue governmental restriction of the procedure—after the safety issues have been sufficiently resolved—unconstitutionally intrudes on the individual’s procreative liberty.<sup>84</sup> CRISPR/Cas9’s controversial nature would not deter the Court from recognizing a fundamental right in its use. The Court decided the right to privacy included abortion, after all, when the nation was vehemently divided over a woman’s right to the procedure.<sup>85</sup> Furthermore, no precedent in the Supreme Court’s history applies seamlessly to germline editing. Using CRISPR/Cas9 modification is a novel fact scenario with which the Court will eventually have to grapple.

This Part analyzes whether the individual is entitled to use CRISPR/Cas9 procedures as a fundamental privacy right. The first section will outline an individual’s right to privacy in general. As that section indicates, the unique contours of genetic engineering requires the Court to analyze the issue through either a minor’s right to bodily integrity or procreative liberty. The next section points out how CRISPR/Cas9 can determine how burdensome a future child will be. It will analyze whether this determination is important in establishing a fundamental right, as it is in the abortion

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*Plessy v. Ferguson*, 163 U.S. 537 (1896), in *Brown v. Bd. of Educ. of Topeka*, 347 U.S. 483, 494–95, 494 n.11 (1954).

<sup>80</sup> ROGER GOSDEN, *DESIGNING BABIES: THE BRAVE NEW WORLD OF REPRODUCTIVE TECHNOLOGY* 63 (W. H. Freeman and Company ed., 1999).

<sup>81</sup> See Thomas S. Patterson, Note, *The Outer Limits of Human Genetic Engineering: A Constitutional Examination of Parents’ Procreative Liberty to Genetically Enhance Their Offspring*, 26 HASTINGS CONST. L.Q. 913, 931 (1999).

<sup>82</sup> *Id.* at 927–28.

<sup>83</sup> See JOHN A. ROBERTSON, *CHILDREN OF CHOICE: FREEDOM AND THE NEW REPRODUCTIVE TECHNOLOGIES* 163–64 (1994) (defending positive genetic engineering on procreative liberty grounds); Attanasio, *supra* note 6, at 1288 (concluding genetic engineering could be justified on right to privacy grounds at the expense of equality concerns).

<sup>84</sup> See ROBERTSON, *supra* note 83, at 163–64.

<sup>85</sup> See, e.g., *Roe v. Wade and Its Impact*, U.S. HISTORY, <http://www.ushistory.org/us/57d.asp> [<https://perma.cc/C62Y-LF4W>].

context. The next section asks why a parent can select traits indirectly through abortion but not through less costly gene editing. The final section will explore how the right to privacy framework deals with a minors' right to bodily integrity. The Supreme Court traditionally protects minor's decisions against their parents' interests if the minors are mature enough to make the decision.<sup>86</sup> However, the Court does not hold this right against parents when they treat the child before that mature age, and for that reason, the minor does not have prenatal autonomy interests.<sup>87</sup>

### A. *The General Right to Privacy*

*Griswold v. Connecticut*<sup>88</sup> was the first case to consider the constitutional right to privacy regarding family planning choices.<sup>89</sup> A Connecticut statute prohibited the sale of contraceptives, even to married couples.<sup>90</sup> The Supreme Court struck down the law,<sup>91</sup> holding a "governmental purpose to control or prevent activities constitutionally subject to state regulation may not be achieved by means which sweep unnecessarily broadly and thereby invade the area of protected freedoms."<sup>92</sup> The Court further protected an individual's autonomy interest from unwarranted governmental interference in *Eisenstadt v. Baird*.<sup>93</sup> There, the statute prohibited the sale of contraceptives to just unmarried couples.<sup>94</sup> Striking down the law, the Court protected the "right of the *individual*, married or single, to be free from unwarranted governmental intrusion into matters so fundamentally affecting a person as the decision whether to bear or beget a child."<sup>95</sup> The Court's language foreshadowed the use of the right to privacy in the abortion debate.

One of the most controversial uses of the right to privacy came in the form of *Roe v. Wade*.<sup>96</sup> Establishing the right to obtain an abortion as a fundamental privacy right, the Supreme Court struck down a Texas law prohibiting the procedure.<sup>97</sup> Interestingly, it afforded no rights or even constitutional standing to the fetus, instead framing the issue as the woman's right to procreate against the state's interest in potential life.<sup>98</sup> Given the chance to overturn *Roe* in *Planned Parenthood of Southeastern*

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<sup>86</sup> See, e.g., *Akron v. Akron Ctr. For Reprod. Health, Inc.*, 462 U.S. 416, 439–42 (1983); *Bellotti v. Baird*, 443 U.S. 622, 643–44 (1979).

<sup>87</sup> See *Bellotti*, 443 U.S. at 643–44.

<sup>88</sup> 381 U.S. 479 (1965).

<sup>89</sup> *Id.* at 485–86.

<sup>90</sup> *Id.* at 480.

<sup>91</sup> *Id.* at 486.

<sup>92</sup> *Id.* at 485 (quoting *NAACP v. Alabama*, 377 U.S. 288, 307 (1964)).

<sup>93</sup> 405 U.S. 438 (1972).

<sup>94</sup> *Id.* at 441.

<sup>95</sup> *Id.* at 453.

<sup>96</sup> 410 U.S. 113 (1973).

<sup>97</sup> *Id.* at 164.

<sup>98</sup> *Id.* at 162–64.

*Pennsylvania v. Casey*<sup>99</sup> two decades later, the Court instead reinforced the central holding of *Roe*: “[M]atters, involving the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy, are central to the liberty protected by the Fourteenth Amendment.”<sup>100</sup> After *Roe* and *Casey* it was clear the Court created an independent framework for evaluating these cases.<sup>101</sup> To show, abortion jurisprudence later adopted a host of legal rules and jargon of its own.<sup>102</sup> The right to privacy, however, has always remained the bedrock.<sup>103</sup>

Despite the broad protections of intimate decisions, the Court has not answered whether there is a privacy right in gene editing. We should avoid finding such a right based solely on the sweeping language that upholds the right in some of these foundational privacy cases. Genetic engineering through CRISPR/Cas9, after all, only borrows select elements from abortion jurisprudence. Unlike in *Roe* or *Casey*, the decision does not turn on whether or not to terminate a pregnancy. But like in those cases, the parent’s decision is informed by what burdens come with child-rearing. Germline manipulation falls somewhere in the gray area between the unique abortion framework and procreative rights in general, and for this reason we must analyze it through more specific lenses within the right to privacy doctrine.

### B. Child-Rearing as a Burden

It is an unfortunate fact that children with genetic diseases require more attention, care, and money.<sup>104</sup> The medical costs for children with Down Syndrome, for example, are twelve to thirteen times higher than the costs of those children without the disorder.<sup>105</sup> The hospitalization costs for those with birth defects is over \$2.6 billion each year<sup>106</sup>—and this cost does not include the emotional or foregone opportunity costs.<sup>107</sup> Based on the available statistics, without devaluing those with the condition already, we can conclude children with genetic defects carry additional burdens for the parents.

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<sup>99</sup> 505 U.S. 833 (1992).

<sup>100</sup> *Id.* at 851.

<sup>101</sup> *See id.* at 878–79; *see also Roe*, 410 U.S. at 164–66.

<sup>102</sup> For example, the Court has fumbled to find the appropriate fulcrum between a woman’s right from government interference and the state’s interest in protecting fetal life. The Court’s first attempt was the trimester framework in *Roe*, in which the privacy right did not protect abortions after the first trimester. *Roe*, 410 U.S. at 164–65. The Court later abandoned this approach in *Casey*, now extending the right to abort as far as fetal viability. *Casey*, 505 U.S. at 877.

<sup>103</sup> *See, e.g., Roe*, 410 U.S. at 154.

<sup>104</sup> Ctr. for Disease Control and Prevention, *Birth Defects Are Costly*, MAHONING CTY BD HEALTH (Jan. 27, 2014), <http://www.mahoninghealth.org/health.org/health/birth-defects-are-costly-cdc-features> [https://perma.cc/3728-C28K].

<sup>105</sup> *Id.*

<sup>106</sup> *Id.*

<sup>107</sup> *See id.*

The burden associated with pregnancy and child-rearing is of central importance in abortion cases. The *Roe* opinion pointed out how unwanted child-rearing “may force upon the woman a distressful life and future.”<sup>108</sup> Although it is not clear whether it was referring to the mother or the child’s health (or both), the opinion also noted “[s]pecific and direct harm medically diagnosable even in early pregnancy may be involved.”<sup>109</sup> If the Court was referring to the child, it suggests the child’s prenatal condition is a factor in determining the burdens of motherhood. Regardless, the burden of child-rearing is essential in elevating a woman’s procreative choice to that of a fundamental right.<sup>110</sup> John Robertson, a proponent of unfettered procreative liberty, points out that “[b]ecause expected outcome is so material to reproductive decision making, it implicates the liberty interest both in avoiding and in achieving reproduction.”<sup>111</sup> The fundamental right, as the Court formulated, is the right to terminate the pregnancy.<sup>112</sup> But does this entail the idea that the woman should also be free to control how much of a burden the pregnancy will be? In other words, can the woman *adjust* the burden through gene editing technology by removing genetic disease?

Reproductive technologies that uncover genetic defects, including CRISPR/Cas9, reveal how burdensome a future child will be. They can influence a prospective parent’s choice of whether the embryo is worth the burden and, consequently, whether to continue the pregnancy. Given the Court’s robust protection of this choice, it makes sense that the parent should be able to control the extent of her burden. Why should a parent be able to remove the burden altogether, via an abortion, but not be able to lessen that burden through CRISPR/Cas9 editing?

We can resolve the issue by juxtaposing pre-birth burdens with post-birth burdens. The former are inseparable from the pregnancy process and include the physical tolls of pregnancy, increased travel and clothing costs, social stigma for unmarried women, the opportunity costs, etc.<sup>113</sup> The pain of childbirth needs no iteration here. The woman must bear these hardships whether the child has randomized or preselected genes. Post-birth burdens, on the other hand, only involve the costs of child-rearing after birth, including the accompanying medical costs, diapers,

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<sup>108</sup> *Roe*, 410 U.S. at 153.

<sup>109</sup> *Id.*

<sup>110</sup> *See* *Planned Parenthood v. Casey*, 505 U.S. 833, 852 (1992) (reaffirming *Roe*’s conclusion that the burdens of child-rearing are inseparable from the termination decision, as the mother is “subject to anxieties, to physical constraints, to pain that only she must bear. . . . Her suffering is too intimate and personal for the State to insist, without more, upon its own vision of the woman’s role. . . .”). This section of the opinion also suggests pregnancy imposes unfair burdens on women specifically. *See id.*; *see also* ROBERTSON, *supra* note 83, at 152 (“[P]ersons have a right not to procreate because of the physical, psychological, and social burdens that reproduction entails, with the person directly affected the best judge of when reproduction is too burdensome.”).

<sup>111</sup> ROBERTSON, *supra* note 83, at 152.

<sup>112</sup> *See id.*

<sup>113</sup> *See Roe*, 410 U.S. at 153.



food, education, etc.<sup>114</sup> Genetic modification only affects the burdens of the already-born child.<sup>115</sup> Although the Court does not explicitly distinguish the burdens in this manner, the language from *Roe* and *Casey* reveals it is really only concerned with the postnatal burdens.<sup>116</sup> Moreover, the Court protects the right to terminate a pregnancy when the mother intends others to raise the child through adoption.<sup>117</sup> The mother avoids the post-birth burdens in that scenario. Even though the Court used broad language to describe the “burdensome” factor in abortion decisions,<sup>118</sup> and that factor is secondary to the right from governmental interference,<sup>119</sup> the clear implication is that the Court considers only those burdens inherent in carrying a fetus to term. Thus, the “burden” argument fails to establish a fundamental child-rearing right in CRISPR/Cas9 germline editing.

### C. Abortion, ARTs, and Negative Eugenics

Abortion creates the ability to discriminate based on genetic disposition. A woman may choose to terminate a pregnancy upon discovery of the fetus’s genetic abnormalities.<sup>120</sup> If this is ever the case, it is usually because the child carries a debilitating disorder.<sup>121</sup> Other artificial reproductive technologies like IVF and PGD also provide prospective parents this option.<sup>122</sup> Because it rejects certain traits, this process is a form of negative eugenics.<sup>123</sup> The practical function of PGD is to single out favorable genes, usually in situations where there is a high risk the offspring will carry a genetic disease.<sup>124</sup> Although an individual’s procreative right to an IVF procedure has never come before the Supreme Court, there is good reason to believe the

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<sup>114</sup> *What It Costs to Have and Raise a Baby*, WEBMD, <https://www.webmd.com/baby/what-it-costs-to-have-and-raise-a-baby>.

<sup>115</sup> Of course, fetuses with genetic diseases or disorders might incur more costs pre-birth than a fetus without a disease or disorder. But for purposes of the argument these costs are negligible compared to the additional post-birth costs.

<sup>116</sup> See *Planned Parenthood v. Casey*, 505 U.S. 833, 928 (1992) (Blackmun, J., concurring); see also *Roe*, 410 U.S. at 153.

<sup>117</sup> See *Casey*, 505 U.S. at 881 (discussing how informed consent statutes may include information on adoptions).

<sup>118</sup> See *Roe*, 410 U.S. at 153 (noting how maternity can lead to a “distressful life and future,” unwanted child care, and psychological harm in general).

<sup>119</sup> See *Casey*, 505 U.S. at 846.

<sup>120</sup> See Wendy F. Hensel, *The Disabling Impact of Wrongful Birth and Wrongful Life Actions*, 40 HARV. C.R.-C.L.L. REV. 141, 142 (2005) (noting that parents have sued under the tort of wrongful birth alleging they would have aborted the child had the impairment been disclosed).

<sup>121</sup> See *id.* (explaining birth defects, like Tay-Sachs disease, can be detected in genetic testing).

<sup>122</sup> For explanations on how these technologies work, see Section I.B.

<sup>123</sup> Daniel J. Kerles, *From Eugenics to Patents: Genetics, Law, and Human Rights*, 75 ANN. HUM. GENETICS 326, 327 (2011).

<sup>124</sup> See *PGD and IVF Costs*, *supra* note 47.



Court would protect it as a fundamental right. In 2002, for example, the Court of Human Rights in Costa Rica ruled a prohibition on IVF violated the individual's right to privacy, personal integrity, and family formation.<sup>125</sup> These reproductive procedures, after all, turn on the decision to bear children, the essential component in the fundamental right.<sup>126</sup>

So if there is a fundamental right to eliminate potential life altogether based on its traits, is there a fundamental right to *change* those traits? Why should woman have to go through these expensive artificial reproductive technologies or an abortion to achieve the same outcome? John Robertson argues the right to avoid procreation after knowing the child's genetic disposition entails the right to select those traits.<sup>127</sup>

However, the procreative right only *incidentally* affords the choice to discriminate based on genetics. The decision of whether or not to bear children necessarily creates a form of negative eugenics. Just because the Court protects reproductive decisions does not mean it protects potential side effects of those decisions. In one of its broadest conceptions of the right, the Court ruled that the individual is "free from unwarranted governmental intrusion into matters so fundamentally affecting a person as the decision whether to bear or beget a child."<sup>128</sup> The Court never mentioned—let alone cautioned against—negative eugenics as an unintended consequence of abortion. This should come as no surprise. Given the cost, physical and emotional strain, and societal stigma associated with abortion, prospective parents have little incentive to select traits via abortion.<sup>129</sup> If anything, they would probably undergo an abortion only for the most debilitating conditions like sickle cell anemia or Huntington's disease. The same is true for IVF and PGD. It is hardly imaginable a parent would choose these procedures unless there was already a substantial risk the embryo would carry a genetic disease. The price tags for tall or blue-eyed genes hardly seems worth the \$3,500,<sup>130</sup> especially considering there are no guarantees.<sup>131</sup> But that is what makes CRISPR/Cas9 modification so unique and so practical. CRISPR/Cas9 strips away the trait choosing component of abortions, and it does so at an incredibly low cost.<sup>132</sup> The money, time, and emotional toll exhausted in choosing traits through PGD, IVF,

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<sup>125</sup> Lynn M. Morgan, *IVF Ban Lifted in Costa Rica: A Success for Reproductive Rights?*, PLOS BLOGS (Mar. 30, 2016), <http://blogs.plos.org/globalhealth/2016/03/ivf-ban-lifted-in-costa-rica-a-success-for-reproductive-rights> [<https://perma.cc/PTZ4-25L7>]. See also Nicole L. Cucci, *Constitutional Implications of In Vitro Fertilization Procedures*, 72 ST. JOHN'S L. REV. 417, 423–31 (1998) (discussing how IVF is constitutionally protected under the right to privacy doctrine).

<sup>126</sup> See *Planned Parenthood v. Casey*, 505 U.S. 833, 857 (1992) (reaffirming that *Roe* protects the right to decide whether to bear a child or not).

<sup>127</sup> See ROBERTSON, *supra* note 83, at 152.

<sup>128</sup> *Eisenstadt v. Baird*, 405 U.S. 438, 453 (1972).

<sup>129</sup> See *Roe v. Wade*, 410 U.S. 113, 153 (1973).

<sup>130</sup> *PGD and IVF Costs*, *supra* note 47.

<sup>131</sup> See *id.* (discussing success rates).

<sup>132</sup> See Barnett, *supra* note 18, at 565.

and abortion are stripped away.<sup>133</sup> But, within its abortion jurisprudence, this particular feature of reproductive decision-making is not what the Court protects. The Court would have to fine-tune the existing privacy right to conform to CRISPR/Cas9 germline editing or create a new fundamental right altogether.

*D. A Minor's Right to Bodily Autonomy*

CRISPR/Cas9 does not involve editing the germline of oneself. The process involves modifying a human embryo, which itself carries no legal status. But because the changes affect another future individual, some legal scholars raise the issue of whether germline editing violates the embryo's autonomy rights as a minor.<sup>134</sup> Germline edits, as opposed to somatic cell treatments, are permanent changes not only for the affected minor but for the minor's future children (and for many subsequent generations).<sup>135</sup> These changes have a more obdurate impact than the choice of education, for example, because the minor can renounce those teachings once she is a legal adult. So which constitutional rights and liberties protect the minor against his parents' decision to genetically modify him?

The Supreme Court frequently upholds a minor's right to bodily integrity through the right to privacy doctrine.<sup>136</sup> In fact, the Court treats minors' decisions regarding abortion differently than choosing other medical treatments for themselves.<sup>137</sup> Treating minors for illnesses is generally uncontroversial, and this probably accounts for the difference. Consent to medical procedures mostly exists in the realm of state statutes and common law.<sup>138</sup> Medical treatment of minors only touches the brim of constitutional law in rare, specific circumstances.<sup>139</sup> Even most of those cases invoke the right to *refuse* medical treatment, like when parents preclude treatment for religious reasons.<sup>140</sup>

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<sup>133</sup> *Id.* at 562–65.

<sup>134</sup> See ROBERTSON, *supra* note 83, at 162 (commenting how genetic engineering may violate the autonomy rights of the minor); see also PATTERSON, *supra* note 81, at 931 (arguing the Court has not established sufficient fetal rights to make the determination of whether they have independent liberty interests).

<sup>135</sup> Barnett, *supra* note 18, at 556.

<sup>136</sup> B. Jessie Hill, *Medical Decision Making By And On Behalf of Adolescents: Reconsidering First Principles*, 15 J. HEALTH CARE L. & POL'Y 37, 48 (2012) [hereinafter Hill, *Medical Decision Making*] (explaining the Court's outlining of minors' constitutional privacy rights through a series of cases involving parental consent or notice before abortions).

<sup>137</sup> *Id.* at 43.

<sup>138</sup> See, e.g., *Custody of a Minor*, 379 N.E.2d 1053, 1062 (Mass. 1978) (finding the state cannot overturn parental refusal of minor's treatment where the child's life was not in danger); *Younts v. St. Francis Hosp. & Sch. of Nursing, Inc.*, 469 P.2d 330, 337 (Kan. 1970) (holding a minor's consent is contingent on his or her understanding of the risks and benefits involved).

<sup>139</sup> See *Custody of a Minor*, 379 N.E.2d at 1062; *Younts*, 469 P.2d at 337.

<sup>140</sup> See Andrea Molinelli et al., *Legal Guardians and Refusal of Blood Transfusion*, 7

At first glance, one might deduce minors have a robust right to privacy in medical treatment decisions. A lengthy line of Supreme Court cases protect the minor's right to bodily integrity against statutes that demand parental consent.<sup>141</sup> However, these cases almost exclusively involve decisions regarding contraceptives or abortions, i.e., reproductive capacity.<sup>142</sup> As in defining an individual's right to make medical decisions,<sup>143</sup> the Court's reasoning differs in regard to this category of decision-making.

Only several years after deciding *Roe*, the Court confronted a minor's right to an abortion in *Planned Parenthood of Central Missouri v. Danforth*.<sup>144</sup> Among other provisions, a Missouri statute required a minor present written consent from a parent in order to undergo an abortion.<sup>145</sup> The Court ultimately struck down the statute, upholding the minor's constitutional right to privacy against the wishes of the parent.<sup>146</sup> Justice Blackmun ruled, "[a]ny independent interest the parent may have in the termination of the minor daughter's pregnancy is no more weighty than the right of privacy of the competent minor mature enough to have become pregnant."<sup>147</sup> The Court demanded a compelling state interest to justify this parental veto power, and it ultimately found none.<sup>148</sup> Interestingly, the Court emphasized that minors possess constitutional rights, even if the state has broader authority to regulate children's activities more than adults.<sup>149</sup>

Where *Danforth* avoided the minor age analysis, *Bellotti v. Baird*<sup>150</sup> confronted it head-on. *Bellotti* also involved a state statute requiring parental consent before the minor could obtain an abortion.<sup>151</sup> However, the Court ruled the statute was unconstitutional on distinct grounds.<sup>152</sup> The statute did not provide an exception where the minor was sufficiently mature and well-informed to make the decision on her own behalf.<sup>153</sup> In other words, whether a minor's right to privacy trumps the interests of the parents (and, consequently, the state) depends in part on the minor's decision-making capacity.<sup>154</sup> The state must afford the minor an opportunity to prove, before

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NCIB 319, 319–22 (2009) (discussing several statutes and cases related to Jehovah's Witnesses refusing blood transfusion for their children).

<sup>141</sup> See Hill, *Medical Decision Making*, *supra* note 136, at 48.

<sup>142</sup> See *infra* text accompanying notes 144–55.

<sup>143</sup> See *infra* Part III.

<sup>144</sup> 428 U.S. 52 (1976).

<sup>145</sup> *Id.* at 58.

<sup>146</sup> *Id.* at 74.

<sup>147</sup> *Id.* at 75.

<sup>148</sup> *Id.*

<sup>149</sup> See *id.* Justice Blackmun, in making this claim, cites a number of cases that held juveniles retain constitutional rights, even if they are not absolute.

<sup>150</sup> 443 U.S. 622 (1979).

<sup>151</sup> *Id.* at 625.

<sup>152</sup> *Id.* at 650.

<sup>153</sup> *Id.* at 647–48.

<sup>154</sup> See Hill, *Medical Decision Making*, *supra* note 136, at 66–67.

a judicial body, her competence in making this decision as a “bypass” of the parental consent requirement.<sup>155</sup>

These cases make clear two points: (1) The minor’s competence to make procreative decisions is an integral factor in delegating this decision-making authority, and (2) even where this competence is accepted, the courts or the parents may still be able to override this decision if either believes the procedure is not in the minor’s best interest.<sup>156</sup> This framework was further explained by B. Jessie Hill in her article on the subject:

If . . . minors’ bodily integrity rights extend beyond the abortion context, and if the mature-minor doctrine is not just an exception to but rather fundamentally inconsistent with a presumption of parental decision-making authority, it must be true that, to the extent minors possess a constitutional right to bodily integrity, that right overrides the common-law default rule of parental decision making for adolescents.<sup>157</sup>

Here the Court upholds a minor’s right to make autonomous health choices, and it has done so only where the minor is of sufficient age and maturity to make those determinations.<sup>158</sup> This is known as the mature-minor doctrine.<sup>159</sup> The primary issue in these cases often boils down to whether the parents or the minor has the best decision-making capacity.<sup>160</sup> The Court strikes down state statutes that require parental consent for medical treatment where (1) the minor has achieved an appropriate age to make the decision, and (2) the state has no other compelling interest, particularly in safety.<sup>161</sup> The strength of the mature-minor doctrine is indicated in several other cases. In its most extreme application, the Illinois Supreme Court upheld a seventeen-year-old’s decision to refuse treatment for leukemia.<sup>162</sup> The Court, however, weighed this right against legitimate state interests, including the “preservation of life,” “protecting the interests of third parties,” “prevention of suicide,” and “maintaining the ethical integrity of the medical profession.”<sup>163</sup> Although this case involved the refusal of medical treatment, it highlights how courts rigorously uphold the mature-minor doctrine in both state and federal cases.<sup>164</sup>

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<sup>155</sup> *Bellotti*, 443 U.S. at 643.

<sup>156</sup> Hill, *Medical Decision Making*, *supra* note 136, at 62.

<sup>157</sup> *Id.* (internal citations omitted).

<sup>158</sup> *See id.* at 42.

<sup>159</sup> *See id.*

<sup>160</sup> *See id.* at 40, 46, 57.

<sup>161</sup> *Id.* at 62–72.

<sup>162</sup> *In re E.G.*, 549 N.E.2d 322, 326–28 (Ill. 1989).

<sup>163</sup> *Id.* at 328 (internal citations omitted).

<sup>164</sup> *See id.*

So how does this constitutional framework play out in CRISPR/Cas9 germline modification? The first issue is the mature-minor doctrine. One might argue the minor's consent is overridden by the time he is mature enough to make a decision regarding his genetic disposition. By that reasoning, the minor's autonomy interest is always impeded by germline editing. However, the minor can never consent to his genetic makeup at the sufficiently mature age. This must necessarily be the case, as germline editing is infeasible once the minor reaches that age.<sup>165</sup> As far as the mature-minor doctrine is involved, choosing to remove genetic disease from the embryo is indistinguishable from choosing the child's kindergarten school. In both scenarios, the offspring is not at the appropriate age to make the informed decision for himself, a necessary precondition to the mature-minor doctrine.<sup>166</sup> In addition, once he is sufficiently mature, the minor has the option of selecting somatic cell therapy to change a genetic condition (most of the time).<sup>167</sup> This choice mirrors traditional areas reserved for parental discretion, like education, nutrition, and upbringing location.<sup>168</sup> The minor can reject or accept any of these after emancipation.<sup>169</sup> Moreover, although the effects are permanent, the Court treats this fact as merely incidental to the broader privacy concerns.<sup>170</sup>

Even if treated as a purely medical procedure, CRISPR/Cas9 editing does not violate any of the minor's decision-making autonomy. Genetic manipulation—almost by definition—imparts greater and more enduring effects on the minor than most other parental choices on her behalf.<sup>171</sup> Because the minor never receives the opportunity to consent for such invasive treatment, one could conclude a CRISPR/Cas9 modification of the minor's DNA *necessarily* intrudes his decision-making autonomy. That argument overlooks the Supreme Court's narrow construct of the privacy right as applied to minors. From the framework in *Danforth* and *Bellotti*, the Court treats the *opportunity* to make a medical decision as necessary to invoke this right.<sup>172</sup> The Constitution does not protect those decisions made before the sufficiently mature

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<sup>165</sup> See Barnett, *supra* note 18, at 555.

<sup>166</sup> Cf. *In re E.G.*, 549 N.E.2d at 327–38.

<sup>167</sup> Although not conducive to treat every prenatal condition, somatic cell therapy has been effective in treating rarer diseases like severe combined immunodeficiency (SCID) and some professionals believe it will one day be used to treat HIV. There are numerous examples of diseases which both somatic and germline editing can treat. See, e.g., Fulvio Mavilio & Giuliana Ferrari, *Genetic Modification of Somatic Stem Cells*, 9 EMBO REP. 564, 564–69 (2008), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3327547/> [<https://perma.cc/ENU3-PZTJ>].

<sup>168</sup> See ROBERTSON, *supra* note 83, at 164.

<sup>169</sup> See Kirsten Rabe Smolensky, *Creating Children with Disabilities: Parental Tort Liability for Preimplantation Genetic Interventions*, 60 HASTINGS L.J. 299, 342 (2008).

<sup>170</sup> See ROBERTSON, *supra* note 83, at 164.

<sup>171</sup> See *id.* (“[G]enetic enhancement might have a far greater effect on offspring than postbirth efforts.”).

<sup>172</sup> See *Bellotti v. Baird*, 443 U.S. 622, 647–48 (1979); cf. *Planned Parenthood of Central Missouri v. Danforth*, 428 U.S. 52, 75 (1976).

age<sup>173</sup>—if it did, all invasive medical treatments before maturity would be placed under strict scrutiny.<sup>174</sup> CRISPR/Cas9 modification, as discussed above, resembles a medical treatment with permanent effects rather than a procreative option.<sup>175</sup> Consequently, the discussion of protecting minors' bodily autonomy should mirror a situation where a parent consents for the child to undergo an invasive—but therapeutic—operation before the appropriate age of consent. Although there is little case law on this point,<sup>176</sup> therapeutic procedures for minors do not directly implicate a child's autonomy interests as much as, for instance, choosing an abortion or buying contraceptives.<sup>177</sup> There is no well-defined autonomy right for such procedures before the age of maturity.<sup>178</sup>

The legal concepts of fetal harm and wrongful life also shed light on a minor's autonomy. Although the modification took place while the individual was an embryo, could a genetically modified minor claim she was harmed from CRISPR/Cas9 germline editing? In *Roe*, the Supreme Court declared that “the word ‘person’ as used in the Fourteenth Amendment, does not include the unborn.”<sup>179</sup> However, numerous states provide a cause of action for post-birth defects where the cause of the injury happened while the individual was *in utero*.<sup>180</sup> One of the most prominent examples comes from *Smith v. Brennan*.<sup>181</sup> There, the New Jersey Supreme Court held that a negligent driver was liable for causing a child's post-birth deformities.<sup>182</sup> It held the child was entitled to redress regardless of his personhood status at the time of the injury's cause.<sup>183</sup> In addition, thirty-one states and the District of Columbia afford mothers

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<sup>173</sup> See *Bellotti*, 443 U.S. at 635.

<sup>174</sup> As *Bellotti* afforded “mature” minors the opportunity to exercise a fundamental right in abortion and thus invokes strict scrutiny over a burdensome law, the Court would presumably apply the same standard of review to a medical procedure with similar permanent and life-long consequences. See *id.* at 643.

<sup>175</sup> See generally Barnett, *supra* note 18 (discussing how CRISPR permanently removes genes).

<sup>176</sup> See ROBERTSON, *supra* note 83, at 167. Reflecting the uncontroversial nature of prenatal medication for even nontherapeutic purposes, Robertson argued “[a]s long as [prenatal medications] are safe, effective, and likely to benefit offspring, they would no more impermissibly objectify or commodify offspring than postnatal enhancement efforts do.” *Id.*

<sup>177</sup> See, e.g., *Bellotti*, 443 U.S. at 648.

<sup>178</sup> See Hill, *Medical Decision Making*, *supra* note 136, at 39–49.

<sup>179</sup> *Roe v. Wade*, 410 U.S. 113, 158 (1973).

<sup>180</sup> *State Laws on Fetal Homicide and Penalty-Enhancement for Crimes Against Pregnant Women*, NAT'L CONF. OF ST. LEGISLATURES (2018), <http://www.ncsl.org/research/health/fetal-homicide-state-laws.aspx> [<https://perma.cc/7UHN-84A2>] [hereinafter *State Laws on Fetal Homicide*]. At least thirty-eight states have enacted fetal homicide laws, and twenty-three of those states extend such laws to the earliest stages of pregnancy. *Id.* See also 18 U.S.C. § 1841 (2012) (making it a federal crime to cause death or serious bodily injury to a child who was in utero at the time of the offense).

<sup>181</sup> 157 A.2d 497 (N.J. 1960).

<sup>182</sup> *Id.* at 505.

<sup>183</sup> *Id.* at 504.



a cause of action for the birth of a healthy child where the mother does not want to give birth.<sup>184</sup> These latter cases are known as “wrongful birth” cases.<sup>185</sup> Although state courts frequently rule against plaintiffs in these cases, they have achieved some degree of success.<sup>186</sup>

It is not difficult to foresee a child born with CRISPR/Cas9 germline modifications bringing an action against his parent, especially if the procedure inadvertently causes harm. The parent can also bring a claim for “wrongful life” if the treating physician was negligent in editing the embryo. However, these precedents have minimal significance to the minor’s constitutional rights against the parent or state. Unlike a minor’s right to privacy, the minors’ autonomy here is protected solely through state tort law. The Seventh Circuit recently dismissed a fetal harm case for lack of subject matter jurisdiction.<sup>187</sup> Consequently, as this Note will discuss further in Part III, the state legislatures and courts are the best arbitrators for these kinds of claims. Localized populations can more efficiently assert their values over fetal harm and wrongful life causes of action. The decentralized system is especially advantageous for the issue because state populations vehemently differ on the fetus’s right to life.<sup>188</sup> Although the Court may consider these state cases in determining the minor’s autonomy interests, they are not dispositive to its ultimate decision.

### III. CRISPR/CAS9 AND MEDICAL AUTONOMY

Genetic modification is invariably a medical procedure. Even if the Supreme Court refuses to recognize CRISPR/Cas9 germline editing as an exercise of one’s right to privacy, it may recognize the practice as an exercise of medical autonomy. A ban on private treatment, after all, stands in stark contrast to the American laissez-faire tradition.<sup>189</sup> The virtue of unencumbered medical access stretches back to 1914 when Justice Cardozo emphasized that, “[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body. . . .”<sup>190</sup>

Once the procedure is proven safe, which (if any) constitutional safeguards protect the individual from unwanted government interference? Do these safeguards take the form of a fundamental right or a lesser liberty interest? The Court has a rich history of individuals claiming a right to access medical treatment.<sup>191</sup>

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<sup>184</sup> Hensel, *supra* note 120, at 153.

<sup>185</sup> *Id.* at 143.

<sup>186</sup> *See id.* at 161 n.117 (noting that only three jurisdictions—California, New Jersey, and Washington—now recognize these kinds of actions).

<sup>187</sup> *See In re Straw*, 720 F.App’x 298 (7th Cir. 2017).

<sup>188</sup> *See State Laws on Fetal Homicide*, *supra* note 180, at 180.

<sup>189</sup> *Schloendorff v. Soc’y of New York Hosp.*, 105 N.E. 92, 93 (N.Y. 1914), *abrogated by Bing v. Thunig*, 143 N.E.2d 3 (N.Y. 1957).

<sup>190</sup> *Id.*

<sup>191</sup> *See generally* B. Jessie Hill, *The Constitutional Right to Make Medical Treatment*



One of the most compelling arguments for medical autonomy came from *England v. Louisiana State Board of Medical Examiners*.<sup>192</sup> In this “mostly forgotten case,”<sup>193</sup> the Fifth Circuit ruled the state medical board could not deny licensing to chiropractors.<sup>194</sup> Although the source of the individual protection is unclear, the language points to a substantive due process right: “[T]he state cannot deny to any individual the right to exercise a reasonable choice in the method of treatment of his ills . . . .”<sup>195</sup> It is worth noting that this case arrived long after the “Lochner era,” where the Supreme Court expanded individual rights through the substantive due process mechanism.<sup>196</sup> Within the next decade, however, individual protections took the form of right to privacy, and substantive due process rights lost their former prestige.<sup>197</sup>

However, public interest often trumps this medical autonomy, and this is the case with CRISPR/Cas9 technology. B. Jessie Hill explores at length how the Court treats such claims in her article *The Constitutional Right to Make Medical Treatment Decisions: A Tale of Two Doctrines*.<sup>198</sup> This Part will analyze the strength of what Hill coined the “right to make medical treatment choices”<sup>199</sup> as applied to CRISPR/Cas9 procedures. First, the “maternal health” exception in abortion cases reveals the Court’s strong deference to an individual’s health over state interest.<sup>200</sup> This section discusses how the Court’s reasoning in the “partial-birth” abortion cases reinforces autonomous medical decisions. The next section, however, analyzes cases where the Court deferred to the legislature in regulating medical treatments. These cases lend to the conclusion that public health concerns trump autonomy interests, even when the legislation does not support the fact-finding.<sup>201</sup> The final section discusses why this “deference” approach (conveniently) avoids the issue of whether there is a right to create disabilities in embryos. Ultimately, while the Court might recognize some lesser liberty interest in accessing CRISPR/Cas9 for germline changes, it would defer to the government’s fact-finding and compelling interest in protecting public welfare.

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*Decisions: A Tale of Two Doctrines*, 86 TEX. L. REV. 277 (2007) [hereinafter Hill, *The Constitutional Right*] (discussing how the Court treated individual claims to access medical treatments against government regulations).

<sup>192</sup> 259 F.2d 626 (5th Cir. 1958).

<sup>193</sup> Hill, *The Constitutional Right*, *supra* note 191, at 279.

<sup>194</sup> *England*, 259 F.2d at 627.

<sup>195</sup> *Id.*

<sup>196</sup> See Sujit Choudhry, *The Lochner Era and Comparative Constitutionalism*, 2 INT’L J. CONST. L. 1, 7 (2004).

<sup>197</sup> *Id.* at 11.

<sup>198</sup> See Hill, *The Constitutional Right*, *supra* note 191, at 294–304.

<sup>199</sup> *Id.* at 291.

<sup>200</sup> See *Roe v. Wade*, 410 U.S. 113, 164–65 (1973); see also Eugene Volokh, *Medical Self-Defense Prohibited Experimental Therapies, and Payment of Organs*, 120 HARV. L. REV. 1813, 1827 (2007).

<sup>201</sup> See *infra* notes 210–26 and accompanying text.

### A. Medical Self-Defense

The maternal health exception is a bastion for medical autonomy. Replete in abortion jurisprudence, the exception requires the state to permit abortions when the mother's life or health is at stake.<sup>202</sup> In *Roe v. Wade*, the Supreme Court traced the maternal health requirement back to Roman laws on abortion and detailed its roots in U.S. history and tradition.<sup>203</sup> The Court reaffirmed the need for the exception in *Planned Parenthood v. Casey*, noting a law restricting post-viable abortions is justified so long as it “contains exceptions for pregnancies which endanger the woman’s life or health.”<sup>204</sup> Eugene Volokh argued this line of cases actually protects two separate but interrelated rights: (1) the right to an abortion, and (2) the right to “defend oneself using medical care.”<sup>205</sup> Indeed, this medical “necessity” component of abortion is generally uncontroversial.<sup>206</sup> As of 2007, only ten to fifteen percent of Americans believed abortion should be banned regardless of this exception.<sup>207</sup> However, while the exception protected the mother’s “life or health”<sup>208</sup> in explicit terms, there is a noteworthy rift between “life” and “health.”<sup>209</sup> The Court explored this rift in the partial-birth abortion cases.

The partial-birth abortion cases are unique because they do not directly implicate procreative rights. In both cases, *Stenberg v. Carhart (Carhart I)*<sup>210</sup> and *Gonzalez v. Carhart (Carhart II)*,<sup>211</sup> the issue did not involve the decision to bear children.<sup>212</sup> The plaintiff mothers in each case had already decided to undergo an abortion—the Court’s review focused on the *kind* of abortion.<sup>213</sup> The issue, then, revolves around the safety of the procedures and a lack of a medical necessity exception. These cases thus

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<sup>202</sup> See Volokh, *supra* note 200, at 1824–29 (defining and discussing the general history of the medical health exception in abortion cases).

<sup>203</sup> 410 U.S. at 130. Later in the opinion, Justice Blackmun traces this exception to early English common law and most state statutes in the nineteenth and twentieth centuries. See *id.* at 137–41.

<sup>204</sup> 505 U.S. 833, 846 (1992).

<sup>205</sup> See Volokh, *supra* note 200, at 1824.

<sup>206</sup> See *id.* at 1824–25.

<sup>207</sup> *Id.* at 1825.

<sup>208</sup> *Casey*, 505 U.S. at 846 (holding the law must contain exceptions “for pregnancies which endanger the woman’s *life or health*”) (emphasis added); *Roe v. Wade*, 410 U.S. 113, 164 (1973) (holding the state may restrict abortion except where it is “necessary to preserve the *life or health* of the mother”) (emphasis added).

<sup>209</sup> *Casey*, 505 U.S. at 846.

<sup>210</sup> 530 U.S. 914 (2000).

<sup>211</sup> 550 U.S. 124 (2007).

<sup>212</sup> See Hill, *The Constitutional Right*, *supra* note 191, at 291–92.

<sup>213</sup> See *Carhart II*, 550 U.S. at 132–34; *Carhart I*, 530 U.S. at 921–23; see also Hill, *The Constitutional Right*, *supra* note 191, at 291 (“[I]t is important to recognize that *Carhart I* (like *Carhart II*, the second ‘partial-birth’ abortion case) is not about the right to choose abortion in the usual sense.”).

offer an enlightening analysis into how the Court treats issues about autonomous treatment decisions. More importantly, the safety issues in these cases mirror the dynamic between CRISPR/Cas9 germline editing and alternative methods for trait selection.

These cases involve two means of abortion: (1) “dilation and extraction,” or “D&X,”<sup>214</sup> and (2) “dilation and evacuation,” or “D&E.”<sup>215</sup> In *Carhart I*, a Nebraska statute prohibited D&X procedures (partial birth abortions) because the procedure usually entailed the fetus tearing apart.<sup>216</sup> The statute did not include an exception that permitted the procedure where the mother’s life or health was at stake.<sup>217</sup> Nebraska pointed out there was no need for an exception because alternative, safer procedures were already readily available.<sup>218</sup> Because both procedures did not threaten the mother’s life, the question turned on whether a strict “health,” i.e., not “life,” exception was necessary.<sup>219</sup> The Court struck down the Nebraska statute in part because it lacked this exception.<sup>220</sup> Where the law restricts a “particular abortion procedure [that] *could* endanger women’s health,”<sup>221</sup> that law unduly infringes on the woman’s constitutional rights.<sup>222</sup> Justice O’Connor stressed the need for the exception in her dissent and pointed out that this requirement was stronger for pre-viable fetuses.<sup>223</sup> At this point, we can envision a robust individual interest in medical self-defense.

In *Carhart II*, however, the Court reached the opposite outcome. This time the Court considered a federal ban on D&X procedures.<sup>224</sup> Having already determined that the statute was sufficiently tailored, the Court contemplated the lack of a medical necessity exception.<sup>225</sup> Here, the Court ruled the exception was unnecessary because unresolved safety questions were best left for legislative determination:

Considerations of marginal safety, including the balance of risks, are within the legislative competence when the regulation is rational and in pursuit of legitimate ends. When standard medical options are available, mere convenience does not suffice to displace them; and if some procedures have different risks than

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<sup>214</sup> *Carhart II*, 550 U.S. at 136. The procedure is also known as “intact D&E” because it extracts the fetus while it is whole and can still feel pain. *Id.* at 136–37.

<sup>215</sup> *Carhart I*, 530 U.S. at 924.

<sup>216</sup> *See id.* at 921–22.

<sup>217</sup> *Id.* at 930.

<sup>218</sup> *Id.* at 931.

<sup>219</sup> *See id.* at 938.

<sup>220</sup> *Id.* at 937–38.

<sup>221</sup> *Id.* at 938 (emphasis added).

<sup>222</sup> *Id.*

<sup>223</sup> *See id.* at 947–48 (O’Connor, J., concurring).

<sup>224</sup> *Gonzales v. Carhart (Carhart II)*, 550 U.S. 124, 132 (2007) (considering the validity of the Partial-Birth Abortion Ban Act of 2003, 18 U.S.C. § 1531 (2000 ed., Supp. IV)).

<sup>225</sup> *Id.* at 161–67.

others, it does not follow that the State is altogether barred from imposing reasonable regulations.<sup>226</sup>

Interestingly, the Court did not even begin to consider the safety arguments from either party.<sup>227</sup> It instead deferred fact-finding to the legislature and ruled an “as-applied” challenge is necessary to resolve any factual disputes of safety.<sup>228</sup> Thus, while recognizing the need to preserve maternal health in *Carhart I*, the Court ultimately found it was not best-suited to identify “significant health risks.”<sup>229</sup> Although *Carhart II* stressed the need for an as-applied challenge, the ruling did not completely undermine the maternal health exception.<sup>230</sup> B. Jessie Hill argued the additional procedure would still consider the plaintiff’s medical arguments and that “medical issues could still be considered in the context of *preenforcement* as-applied challenges.”<sup>231</sup>

The medical self-defense doctrine does not protect CRISPR/Cas9 germline editing as a safer or more feasible alternative of trait selection. The Court would not grant the same level of protection even if it includes defense of future offspring as tantamount to self-defense. First, the “life” of the fetus is not at stake in genetic engineering, even for therapeutic treatment.<sup>232</sup> The prospective parent would have to claim she is entitled to CRISPR/Cas9 because it benefits her or the embryo’s *health*. Although the plaintiff was able to choose between procedures based on medical consequences in *Carhart I*, the same is not true in the more recent case, *Carhart II*.<sup>233</sup> The parent wishing to germline edit would have to show that the technique is safer in an as-applied challenge. Even then, there is no substantial evidence that CRISPR/Cas9 is inherently safer than the alternatives.<sup>234</sup> Although CRISPR/Cas9 is far more accurate and affordable, it is not safer than IVF or PGD, both of which involve the same embryo-extraction process.<sup>235</sup> As the Court mentioned, “mere convenience

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<sup>226</sup> *Id.* at 166.

<sup>227</sup> *See id.* at 161–68.

<sup>228</sup> *Id.* at 167–68. Reversing this particular issue from *Carhart I*, the Court opined: *Stenberg* has been interpreted to leave no margin of error for legislatures to act in the face of medical uncertainty. . . . A zero tolerance policy would strike down legitimate abortion regulations . . . if some part of the medical community were disinclined to follow the proscription. This is too exacting a standard to impose on the legislative power . . . .

*Id.* at 166 (internal citations omitted).

<sup>229</sup> *Id.* at 129 (quoting *Ayotte v. Planned Parenthood of N. New Eng.*, 546 U.S. 320, 328 (2006)).

<sup>230</sup> *See Hill, The Constitutional Right*, *supra* note 191, at 323.

<sup>231</sup> *Id.*

<sup>232</sup> Many debilitating genetic disorders shorten life, but none immediately threaten the fetus’s health in utero.

<sup>233</sup> *Carhart II*, 550 U.S. at 127; *Stenberg v. Carhart (Carhart I)*, 530 U.S. 914, 915 (2000).

<sup>234</sup> *See Belluck, supra* note 1; *Ledford, Where in the World, supra* note 7.

<sup>235</sup> *See NAT’L ACAD. OF SCI., supra* note 51, at 65; *Ellison, supra* note 6, at 618; *Polcz & Lewis, supra* note 22.

does not suffice to displace”<sup>236</sup> alternative means—in this case, IVF or PGD. Moreover, in *Carhart II* the Court weighed the availability of a health exception against the state’s interest in protecting prenatal life.<sup>237</sup> The state already has a substantial interest in preventing the possible, negative consequences of germline editing.<sup>238</sup> This interest would trump any “life or health” claims a potential parent would make for her offspring.

If *Carhart I* were the standalone decision on partial birth abortions, the case for a right to medical improvement using CRISPR/Cas9 would prove much more robust. By requiring a medical self-defense exception, the Court safeguarded the individual’s medical autonomy. However, *Carhart II*—by refusing to rule over factual disputes of safety—ultimately undermined that autonomy interest. As a result, the individual cannot claim a right to CRISPR/Cas9 through the same reasoning that upheld a maternal health exception.

### *B. The ‘Public Health’ Ceiling*

The Supreme Court has never directly addressed whether an individual has a fundamental right to private medical treatment. In a recent case involving this issue, the D.C. Court of Appeals expressed in unequivocal language: “We do not address the broader question of whether access to medicine might ever implicate fundamental rights.”<sup>239</sup> Furnished with over a century of state and federal cases proposing the question, the Court has yet to answer with clarity. Instead, the Court dodged the issue—resigning it to the outskirts of constitutional law—while addressing narrower questions.<sup>240</sup>

However, the Supreme Court has been much more vocal about the state’s power to regulate medicine in the name of public health.<sup>241</sup> The right to privacy’s focus on the individual is overshadowed by the state interest in population health.<sup>242</sup> A line of cases stretching back to the early twentieth century repeatedly and adamantly assert this state power, especially in the face of untested or fringe medical treatments. *Jacobson v. Massachusetts*<sup>243</sup> in particular was paramount in establishing this state power. This

<sup>236</sup> *Carhart II*, 550 U.S. at 166.

<sup>237</sup> See Volokh, *supra* note 200, at 1829–30 (arguing that while there may be a right to medical self-defense, the State’s interest in regulating the treatment may be greater).

<sup>238</sup> See *Carhart II*, 550 U.S. at 157 (describing how there is an interest in protecting the ethics of the medical profession).

<sup>239</sup> *Abigail All. for Better Access to Dev. Drugs v. Von Eschenbach*, 495 F.3d 695, 701 (D.C. Cir. 2007).

<sup>240</sup> See *id.* at 711–12.

<sup>241</sup> See *United States v. Oakland Cannabis Buyers Coop.*, 532 U.S. 483 (2001); *United States v. Rutherford*, 422 U.S. 544 (1979); *Jacobson v. Massachusetts*, 197 U.S. 11 (1905).

<sup>242</sup> See *Jacobson*, 197 U.S. at 38 (wanting to avoid “the welfare and safety of an entire *population* being subordinated to the notions of a single individual . . .”) (emphasis added); Hill, *The Constitutional Right*, *supra* note 191, at 295.

<sup>243</sup> 197 U.S. 11 (1905) (holding the state’s interest in public health supports mandatory vaccination laws).

throng of cases, originating in *Jacobson*, imposes a figurative “ceiling” for individuals wishing to assert an autonomy interest in obtaining medical treatment.<sup>244</sup> The state, in defending its ban on CRISPR/Cas9 germline editing, would certainly cite to the reasoning in *Jacobson*. CRISPR/Cas9 prohibitions fall in line with the Court’s justification for their constitutionality: protecting the public from potentially harmful treatments. As a result, the Court would defer fact-finding to the legislature, the branch best suited to make a determination whether germline editing was sufficiently safe for public use.

*Jacobson* is considered the “seminal”<sup>245</sup> opinion in health-related cases. The plaintiff challenged Massachusetts’s compulsory vaccination law, claiming the law was “hostile to the inherent right of every freeman to care for his own body and health in such [a] way as to him seems best . . . .”<sup>246</sup> The Court entertained his argument and saw its merits, but concluded the law was sufficiently justified by the state’s interest in protecting the population’s health.<sup>247</sup> Massachusetts, as the ultimate arbiter over questions of public necessity, could invoke its police power to compel individuals into medical treatment.<sup>248</sup> It is important to note that the Court afforded the legislature this power.<sup>249</sup> Moreover, the legislature could determine what was conducive to public health “whether it [is] *in fact or not*.”<sup>250</sup> The Court thus applied rational basis review, the easiest standard to overcome, to public health measures.<sup>251</sup> *Jacobson*’s central holding hasn’t been seriously challenged to this day, solidifying the public health justification in contemporary constitutional law.

When confronted with individual claims for unapproved medicine, the Supreme Court adopted the custom of deferring to the legislature. In *United States v. Rutherford*,<sup>252</sup> terminally ill cancer patients sought access to a drug called Laetrile.<sup>253</sup> The FDA listed Laetrile as a “new drug[,]” had not yet found evidence of its “safe and effective use,” and, consequently, had not approved it for distribution.<sup>254</sup> The District Court created an exception for terminally ill patients because the drugs could not be unsafe to them since their condition led to death regardless.<sup>255</sup> The

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<sup>244</sup> See, e.g., *id.*

<sup>245</sup> Hill, *The Constitutional Right*, *supra* note 191, at 296 (quoting Wendy E. Parnet et al., *Individual Rights Versus the Public’s Health—100 Years After Jacobson v. Massachusetts*, 352 NEW ENG. J. MED. 652, 652 (2005)).

<sup>246</sup> *Jacobson*, 197 U.S. at 26.

<sup>247</sup> *Id.* at 35.

<sup>248</sup> *Id.*

<sup>249</sup> *Id.* at 27 (“The good and welfare of the Commonwealth, of which the legislature is primarily the judge, is the basis on which the police power rests in Massachusetts.”).

<sup>250</sup> *Id.* at 35 (emphasis added).

<sup>251</sup> See *id.* 27–35.

<sup>252</sup> 442 U.S. 544 (1979).

<sup>253</sup> *Id.* at 548.

<sup>254</sup> *Id.* at 546.

<sup>255</sup> *Id.* at 551.



Supreme Court rejected this argument.<sup>256</sup> Instead, it ruled that to grant the exception would “deny the [state’s] authority over all drugs, however toxic or ineffectual . . . .”<sup>257</sup> It then held the state legislature was “entitled to substantial deference”<sup>258</sup> over regulating medication. Similarly, in *United States v. Oakland Cannabis Buyers’ Cooperative (OCBC)*,<sup>259</sup> the Court refused to recognize a right to medicinal cannabis even when the individual suffered from a life-threatening condition.<sup>260</sup> A more recent case also involved obtaining a non-FDA approved drug. The D.C. Circuit in *Abigail Alliance v. Von Eschenbach*<sup>261</sup> considered whether a terminally ill individual held the right to treatment that “met a lower evidentiary hurdle with respect to safety and efficacy.”<sup>262</sup> Unlike in *Rutherford*, the FDA’s initial approval process revealed the drug had potential for therapeutic benefit.<sup>263</sup> The finding, however, was not enough to permeate the public health ceiling; the Court refused to recognize a fundamental right in accessing such treatment, borrowing the “history and tradition” framework from *Glucksberg*.<sup>264</sup> It even rejected a medical necessity defense, as that exception “remains controversial and cannot override a value judgment already determined by the legislature . . . .”<sup>265</sup> Such decisions continue to endorse “the Court’s historical solicitude for the legislature’s ability to freely exercise its police powers to protect the public health.”<sup>266</sup>

The Supreme Court would uphold a legislative ban on CRISPR/Cas9 germline editing as an exercise of the state’s discretion over public health. Much like in *Jacobson*, the state could invoke its police power to protect the public against its potentially harmful effects. Safety issues are the most relevant issue today.<sup>267</sup> But even if these safety issues are mostly resolved through clinical testing, CRISPR/Cas9 carries additional concerns, the fear of positive eugenics being the most salient example. The August 2017 germline experiment already showed the practice could be safe and therapeutic.<sup>268</sup> But even comprehensive, peer-reviewed conclusions of CRISPR/Cas9’s immediate safety would not alleviate every safety concern. For one, subjects might not develop harmful side effects until generations later.<sup>269</sup> As of this

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<sup>256</sup> *Id.* at 552.

<sup>257</sup> *Id.* at 557–58.

<sup>258</sup> *Id.* at 553.

<sup>259</sup> 532 U.S. 483 (2001).

<sup>260</sup> *Id.* at 494.

<sup>261</sup> 495 F.3d 695 (D.C. Cir. 2007).

<sup>262</sup> *Id.* at 699.

<sup>263</sup> *See id.* The FDA allows use of an “investigational drug” where (i) it treats a serious or life-threatening condition, and (ii) there are no practical alternatives. The FDA has the right to deny access where it believes there is a material risk of additional illness or injury. *Id.*

<sup>264</sup> *Id.* at 697 (citing *Washington v. Glucksberg*, 521 U.S. 702 (1997)).

<sup>265</sup> *Id.* at 708.

<sup>266</sup> Hill, *The Constitutional Right*, *supra* note 191, at 302.

<sup>267</sup> *See* Belluck, *supra* note 1; Ledford, *CRISPR Fixes*, *supra* note 54.

<sup>268</sup> Belluck, *supra* note 1.

<sup>269</sup> *See* Ledford, *CRISPR Fixes*, *supra* note 54.



writing, there are no accepted ethical means to fully resolve the safety issues until individuals (and even their offspring) are exposed to the treatment and are observed for long periods. Second, as in *Abigail Alliance*, courts afford the legislature almost absolute power to deny access to private treatment, even where the treatment exhibits some signs of therapeutic benefit before FDA approval.<sup>270</sup> Applying rational basis review, the Court also would not question the efficacy of the legislature's fact-finding of CRISPR/Cas9. The entire scientific, legal, and bioethical community could overwhelmingly endorse the practice and the Court would regardless uphold the legislative regulation. As a new and unsanctioned medical treatment, the public health ceiling ensures the question of CRISPR/Cas9 germline editing merits legislative deference.

Deferential treatment produces several positive outcomes. First, legislatures are more adept at and can marshal greater resources for fact-finding than the courts.<sup>271</sup> In an issue as divisive and complex as CRISPR/Cas9 genetic engineering, its legal treatment turns in large part on the facts presented to the legislature. These facts would presumably include not only medical outcomes, but also the opinions of bioethicists and legal scholars surrounding the procedure's ethical status and social consequences.<sup>272</sup> The legislature is best suited to resolve issues surrounding "social fact,"<sup>273</sup> as they are representative bodies with diverse backgrounds.<sup>274</sup> Second, the population's perspectives on genetic engineering are bound to change with time as the practice becomes increasingly mainstream. A judicial decision on the matter would only cement the prevailing views at the time the Court issues the opinion. Legislatures are more responsive to shifting perspectives on medical advances and can "revisit and revise previous legislative decisions as necessary to adapt them to changing factual circumstances."<sup>275</sup> We can imagine a society warming up to the idea of CRISPR/Cas9 germline editing as an effective means to eradicating genetic

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<sup>270</sup> See *Abigail Alliance*, 495 F.3d at 697. The FDA is the federal agency most likely to oversee CRISPR/Cas9 germline editing regulation. It has control over gene-therapy transfers, especially those that replace DNA components. However, because human embryos are not considered legal persons, the FDA would have to adjust its jurisdiction to include sources that would eventually become legal persons. See Barnett, *supra* note 18, at 577–78 (detailing how the FDA could one day regulate CRISPR/Cas9 germline editing).

<sup>271</sup> See Hill, *The Constitutional Right*, *supra* note 191, at 333 ("[L]egislatures, unlike courts, have vast resources for fact gathering, including large staffs and considerable funds designated for precisely that purpose; subpoena power; and the ability to take as much time as necessary to compile all the relevant information.").

<sup>272</sup> Legislatures often preclude purely ethical opinions or "moral judgments that masquerade as objective fact" from their fact-finding review. Caitlin E. Borgmann, *Rethinking Judicial Deference to Legislative Fact-Finding*, 84 IND. L.J. 1, 9–10 (2009). However, scientists and bioethicists would probably succeed in admitting facts as to CRISPR/Cas9's potential impacts on social inequality and other objectively measurable outcomes. *Id.* at 9.

<sup>273</sup> Hill, *The Constitutional Right*, *supra* note 191, at 334.

<sup>274</sup> See *id.*

<sup>275</sup> *Id.* (citing Neal Devins, *Congressional Factfinding and the Scope of Judicial Review: A Preliminary Analysis*, 50 DUKE L.J. 1169, 1180 (2001)).

diseases from the populace. Given its affordability and accessibility, those who previously claimed the procedure amounted to “playing God”<sup>276</sup> might instead see it as a development in human progress. Advances in medicine are usually fraught with anxiety against unknown effects.<sup>277</sup> It is therefore crucial to resolve these issues via the democratic process. Given mankind’s troubled history with eugenics,<sup>278</sup> perhaps society is now in a position to learn from its mistakes and halt another slide into moral abyss.

### C. *The Problem of Creating Disability*

By deferring to the legislature, courts avoid answering the question of whether or not there is a right to engineer a disability through CRISPR/Cas9. The intuitive response questions the parent’s incentives: why would anyone want to *create* an impairment?

The implied purpose of genetic engineering technologies is to remove impairments and give children a more prosperous, less burdensome future.<sup>279</sup> The motivations to create a disability, rather than remove one, are beyond the scope of this Note. This issue is one the Supreme Court would ultimately have to address if it found a fundamental right in germline editing. The Court would find itself running into more problems than solutions. What counts as a “disability?” Who decides? Can we forbid this practice without devaluing those with preexisting genetic defects?

Shawna Benston introduced and detailed this subject in her article *CRISPR, a Crossroads in Genetic Intervention: Pitting the Right to Health against the Right to Disability*.<sup>280</sup> Benston highlights the many issues associated with engineering disabilities through CRISPR/Cas9.<sup>281</sup> Her article presents the issue as a normative one, inseparable from our social and legal perspectives on disability, the right to health, and what constitutes “harm.”<sup>282</sup> Other legal scholars have pointed out the difficulty in defining a “disability,” sometimes separating the question in medical, social, and civil rights models.<sup>283</sup> Benston ultimately endorses an approach that would allow a

<sup>276</sup> See NAT’L ACAD. OF SCI., *supra* note 51, at 124; Ellison, *supra* note 6, at 610; Patterson, *supra* note 81, at 914.

<sup>277</sup> See Cucci, *supra* note 125, at 419; see also NAT’L ACAD. OF SCI., *supra* note 51, at 143.

<sup>278</sup> See Barnett, *supra* note 18, at 554; Kevin Wang, *CRISPR and the Future of Genome Engineering: A Bold New World*, 10 INTERSECT 2, 8 (2017).

<sup>279</sup> See Barnett, *supra* note 18, at 554 (“CRISPR advocates are enthusiastic about its promise for correcting mutations for serious genetic diseases.”).

<sup>280</sup> Shawna Benston, *CRISPR, A Crossroads in Genetic Intervention: Pitting the Right to Health Against the Right to Disability*, 5 LAWS 1 (2016). For further discussion on this issue, focused instead on preimplantation genetic diagnoses, see Smolensky, *supra* note 169, at 299 (discussing the dilemma as applied to the PGD procedure).

<sup>281</sup> See Benston, *supra* note 280, at 3–4.

<sup>282</sup> See *id.* at 6–9 (highlighting the different definitions of “disability” by the Americans with Disabilities Act (ADA) and the United Nations’s Convention on the Rights of Persons with Disabilities (UNCRPD)).

<sup>283</sup> See Hensel, *supra* note 120, at 146–50.

parent to create these genetic changes as an essential element of individual autonomy.<sup>284</sup> Our concept of “harm” is ever-changing and we should be wary of when the present conception unduly interferes with our individual autonomy:

[T]he law’s protections encompass not only individuals with unavoidable disability but also individuals who abstain from medical cures, individuals whose parents decline medical interventions on their behalf, and even individuals whose disability was *engineered* by themselves or their parents. . . . [I]n a society where identities and communities are actively reconstituting themselves around what were previously understood as “disabilities,” the legal and ethical understanding of “harm” becomes increasingly tentative.<sup>285</sup>

In addition, Benston points out that the debate centers around whether the child is “harmed” if the parent chooses the child’s disability as a necessary condition of the child’s existence.<sup>286</sup> In other words, is the child’s life with the disability worse than no life at all? Benston argues the answer depends on what she calls the “subjunctive-threshold interpretation of harm.”<sup>287</sup>

The Court dodges these thorny dilemmas by deferring to the legislature.<sup>288</sup> The Court would concur the state legislatures are best suited to make this determination. Much like the more general question of whether to permit CRISPR/Cas9 germline editing, the disability issue invokes moral and political debates that are best resolved through a democratic process. First, the Court would have limited precedent to resolve this issue. The New Jersey Supreme Court refused to tackle the predicament when, in one of the first “wrongful birth” cases, it wrote “[a] court cannot say what defects should prevent an embryo from being allowed life such that denial of the opportunity to terminate the existence of a defective child in embryo can support a cause for action.”<sup>289</sup> The New York Court of Appeals expressed unwillingness to even approach the issue.<sup>290</sup> Although there have since been a number of “wrongful life” cases,<sup>291</sup> they fall outside the Supreme Court’s jurisdiction. As state tort actions, the Court can only rely on them as secondary authority.

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<sup>284</sup> See Benston, *supra* note 280, at 4.

<sup>285</sup> *Id.* at 3.

<sup>286</sup> See *id.* at 8–9.

<sup>287</sup> *Id.* at 9.

<sup>288</sup> See, e.g., *Jacobson v. Massachusetts*, 197 U.S. 19–20 (1905); Hill, *The Constitutional Right*, *supra* note 191, at 287–89, 297–98, 302.

<sup>289</sup> *Gleitman v. Cosgrove*, 227 A.2d 689, 693 (N.J. 1967).

<sup>290</sup> See *Becker v. Schwartz*, 386 N.E.2d 807, 812 (N.Y. 1978) (“Whether it is better never to have been born at all than to have been born with even gross deficiencies is a mystery more properly to be left to the philosophers and the theologians.”).

<sup>291</sup> See Hensel, *supra* note 120, at 161 (noting that the courts usually reject “wrongful life” claims on the ground that life is better than no life at all).

Most importantly, the legislature is more responsive to shifting norms and attitudes regarding what constitutes “harm” and, consequently, a “disability.”<sup>292</sup> Much like in the overall question of whether to permit CRISPR/Cas9 germline editing, legislatures can more quickly modify laws in response to changing conceptions of “disability.” “[W]hereas a court’s judgment is ossified in legal precedent as constituting a quasi-legal determination, often without any mechanism for reopening an issue of legislative fact previously decided, legislatures can revisit and revise previous legislative decisions as necessary to adapt them to changing factual circumstances.”<sup>293</sup> The issue sways with public opinion and may be out of reach even to the scientific community.<sup>294</sup> The Supreme Court’s historical position, as a bastion of permanent resolution, does not suffice to meld this normative divide.

#### CONCLUSION

CRISPR/Cas9 technology has been aptly described as a “genetic revolution.”<sup>295</sup> The social, economic, and moral implications of genetic engineering are bound to produce groundbreaking consequences.<sup>296</sup> The normative upheaval may one day rival that of the industrial revolution in modern world history. We are at the dawn of separating the science from the fiction, from reading *Brave New World*<sup>297</sup> less as fable and more as stark prophecy. Faced with such a societal transformation, we should at least begin to consider how to calibrate CRISPR/Cas9 engineering in our existing legal framework. Before implementing a categorical ban, legislatures should take into account scientific, legal, and bioethical views on the practice. More importantly, the Supreme Court must approach the issue with caution and foresight.

Because CRISPR/Cas9 germline editing is so near to the clinical testing phase, a parent may soon assert a fundamental right in its use. She would have a convincing argument. The Court has long protected procreative rights, especially concerning an individual’s decision regarding if and how to raise a child. However, neither the right to privacy nor a right to make medical treatment choices elevates CRISPR/Cas9 use to a full-fledged right. The protections within the right to privacy apply only to the decision of whether to have a child, not the child’s genetic disposition. In addition,

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<sup>292</sup> See *supra* notes 186–88 and accompanying text.

<sup>293</sup> Hill, *The Constitutional Right*, *supra* note 191, at 334 (citing Neal Devins, *Congressional Factfinding and the Scope of Judicial Review: A Preliminary Analysis*, 50 DUKE L.J. 1169, 1169–70, 1179 (2001)).

<sup>294</sup> See Benston, *supra* note 280, at 7.

<sup>295</sup> Wang, *supra* note 278, at 7.

<sup>296</sup> Such a futuristic scenario was already envisioned in such films as *GATTACA* (Columbia Pictures 1997) and *BLADE RUNNER* (Warner Bros. 1982).

<sup>297</sup> See generally ALDOUS HUXLEY, *BRAVE NEW WORLD* (Harper Perennial ed., 1931) (depicting a utopia where children are genetically modified to accommodate their predetermined careers).

the Court almost always defers to the legislature when confronted with unapproved medical treatments. It invokes the police power of the state, coupled with the state's interest in protecting public welfare, to apply a rational basis review to these cases. Legislative deference leads to the most beneficial outcomes. The legislature is the best suited to make these complex judgments, and it is responsive to changing attitudes. Although the Court would not supply a constitutional safeguard, the individual certainly always has the ballot box. In the meantime, we will have to settle for our genes the way they are.