

Human Genome Editing

A Catholic Perspective

Rev. Kevin FitzGerald, SJ

Abstract. With this power to edit our own genes comes the enormous responsibility to determine if, when, how, and why we should, or should not, employ this technology. This article addresses this responsibility from the perspective of the moral tradition and reasoning of the Catholic Church. Past, present, and possible future positions of the Catholic Church regarding human genome manipulation are analyzed in light of the fundamental values that undergird Catholic ethical reasoning, and the significant contributions the Catholic perspective can bring to global deliberations on the responsible use of human genome editing are identified. These contributions represent both opportunities and obligations for the Catholic Church in its continuing tradition of providing health care around the world, especially to those who are the most vulnerable and most in need. *National Catholic Bioethics Quarterly* 17.1 (Spring 2017): 107–122.

Once again, news of the promise and peril of human genetic and genomic medicine is before the public, in particular, advances in genome editing. Considering the global attention genetic knowledge and possible treatments have received over the past hundred years or more, anyone today could reasonably ask, is the world finally ready to reap the benefits and avoid the harms of our rapidly advancing genome editing technology? Of course, one could also reasonably ask, how can we even know whether or not the world is ready?

Rev. Kevin FitzGerald, SJ, PhD, is the Dr. David Lauler Chair of Catholic Health Care Ethics in the Center for Clinical Bioethics at Georgetown University, Washington, DC, and an associate professor of oncology at Georgetown University Medical Center.

The views expressed in the *NCBQ* do not necessarily represent those of the editor, the editorial board, the ethicists, or the staff of The National Catholic Bioethics Center.

It is the goal of this essay to make the reader aware of how contributions of the Catholic Church to biomedicine over the past century continue to enhance global decision making regarding the use of rapidly advancing genetic technologies, especially on human genomes. The distinctive reasoning and values of the Catholic Church provides a framework for achieving the goods of human genome editing while avoiding its harms, especially to the most vulnerable in our societies.

When approaching this issue of human genome editing, it is important to recognize that attempts to manipulate human genomes are not new. Observing that plants and animals transmit and recombine features from one generation to the next and recognizing that the same principles of inheritance apply to human beings, Plato writes,

If a courageous character is reproduced for many generations without any admixture of the moderate type, the natural course of development is that at first it becomes superlatively powerful but in the end it breaks out into sheer fury and madness. . . . But the character which is too full of modest reticence and untinged by valor and audacity, if reproduced after its kind for many generations, becomes too dull to respond to the challenges of life and in the end becomes quite incapable of acting at all.¹

Applying this knowledge of heredity, Plato argues that the most gifted individuals of both sexes should breed, and their children should be carefully educated. The children of inferior couples would be abandoned.²

For the next two thousand years, the knowledge of heredity did not advance much beyond the observations of Plato's time. However, with the coming of the Enlightenment and its emphasis on empirical observation as the proper ground for scientific inquiry, the time was ripe for major advances in the understanding of human genetics, namely, Francis Galton's concept of biometry and Gregor Mendel's study of the gene.

Both of these scientists combined statistical methods with empirical observations to create their new theories. Galton argued that not only physical features, but even behavioral characteristics, had to have a hereditary component, because certain talents run in families to a greater extent than one would predict, even taking social conditions into consideration. Mendel employed relatively simple and clear experiments to demonstrate statistical laws that successfully predict the distribution patterns of certain plant characteristics from one generation to the next.³

Ironically, Galton's work had the greater influence during the late nineteenth century, whereas Mendel's insights lay dormant until the twentieth century. First, the advances in molecular genetics over the past several decades have simultaneously extended the reach of the Mendelian paradigm and reduced the need for Galtonian analysis of population characteristics. Second, along with his biometric analysis, Galton also urged the pursuit of a utopian eugenics program that was not much

1. Plato, *The Statesman*, trans. J. B. Skemp, ed. Martin Ostwald (Indianapolis: Hackett, 1992), 310d–e.

2. Plato, *The Republic*, trans. Desmond Lee, 2nd ed. (London: Penguin Books, 1987), 459e.

3. Friedrich Vogel and Arno G. Motulsky, *Human Genetics*, 2nd ed. (Berlin: Springer-Verlag, 1986), 11–12.

different from the one suggested by Plato. In part, Galton's urgency was spurred by his conclusion that the British upper class, which he believed represented the best of humanity, was not producing enough offspring to maintain its important contribution to the gene pool. Galton's ideas about eugenics received early support and encouragement from both scientists and politicians. However, attempts to implement eugenics programs in the United States during the early decades of the twentieth century and in Germany during the Nazi era resulted in such injustices and destruction that Galton's theory fell into disuse and disrepute.⁴

Interestingly, one institution in the United States that consistently attempted to push back against the surge to implement eugenic public policies was the Catholic Church. This organized resistance has been well documented by Sharon Leon in *An Image of God: The Catholic Struggle with Eugenics*. Leon discusses how during the early twentieth century, the Catholic Church supported initiatives that promoted the common good, such as programs encouraging married couples to have more children and legislation providing for social welfare programs. At the same time, the Church employed extensive public information campaigns and lobbied the government to protect vulnerable communities from eugenic proposals, such as compulsory sterilization and restrictions on immigration from undesirable countries.

The Church's opposition to this eugenics effort was based on two foundations, one grounded in good science and one in Catholic doctrine. From the scientific perspective, Catholic opposition criticized eugenic science for lacking scientific rigor, concealing blatant ethnic and class biases, and ignoring the importance of social and environmental factors in the development of a person's character. From the doctrinal perspective, the Church argued that the government could not violate an innocent individual's bodily integrity, regardless of the supposed biological improvements that might result. In her book's conclusion, Leon states, "The dogged and sustained activism of Catholics made them the primary source of opposition to eugenic sterilization and helped to influence the rejection of negative eugenics initiatives even in places where Catholics did not dominate the public discourse. And at the center of this half-century struggle with eugenics was an unchanging vision of the primacy of all human life."⁵

This unchanging vision of the primacy of all human life remains at the core of the Catholic Church's contribution to the global discussion about how to evaluate and employ the revolutionary advances in medical genetics and genomics. To understand this critical contribution, it will help to focus on three specific aspects of this Catholic moral tradition: (1) why the Church attaches special significance to the primacy of human life, (2) how the vision of this primacy has developed in response to advances in medical genetic technology, and (3) how the resultant vision of the primacy of human life will be useful, even crucial, in the ongoing global discussion about human genome editing.

4. American Society of Human Genetics, "Eugenics and the Misuse of Genetic Information to Restrict Reproductive Freedom," *American Journal of Human Genetics* 64.2 (February 1999): 335–338.

5. Sharon M. Leon, *An Image of God: The Catholic Struggle with Eugenics* (Chicago: University of Chicago Press, 2013), 169.

The Primacy of All Human Life

Gaudium et spes provides an excellent summary of the Church's vision of the fundamental importance of every human life. At the very beginning of this document, the Church's concern for each human being is made clear:

The joys and the hopes, the griefs and the anxieties of the men of this age, especially those who are poor or in any way afflicted, these are the joys and hopes, the griefs and anxieties of the followers of Christ. Indeed, nothing genuinely human fails to raise an echo in their hearts. . . . Hence this Second Vatican Council, having probed more profoundly into the mystery of the Church, now addresses itself without hesitation, not only to the sons of the Church and to all who invoke the name of Christ, but to the whole of humanity. For the council yearns to explain to everyone how it conceives of the presence and activity of the Church in the world of today. . . . This council can provide no more eloquent proof of its solidarity with, as well as its respect and love for the entire human family with which it is bound up, than by engaging with it in conversation about these various problems. The council brings to mankind light kindled from the Gospel, and puts at its disposal those saving resources which the Church herself, under the guidance of the Holy Spirit, receives from her Founder. For the human person deserves to be preserved; human society deserves to be renewed. Hence the focal point of our total presentation will be man himself, whole and entire, body and soul, heart and conscience, mind and will.⁶

There are several important points to glean from this introduction. First of all, the Catholic Church emphasizes that we are all on this journey of life together. Therefore, we need to be in constant communication to find the best ways to bring fulfillment to each life around the world, especially to the poor and afflicted. For Catholics, this global solidarity comes from embracing Christ's mission—the salvation of all humankind. This mission is to be continually worked out in the here and now, addressing the opportunities and challenges of each age in a way that reaches out to everyone in the world, not just members of the Catholic Church, and fosters true human fulfillment for each person on our shared journey toward ultimate fulfillment in God's love.

Later in this same document, the Church expands on the need to remain relevant to the current state of the world by emphasizing the fundamental interdependence of all peoples in the technological age of the 1960s:

One of the salient features of the modern world is the growing interdependence of men one on the other, a development promoted chiefly by modern technical advances. Nevertheless brotherly dialogue among men does not reach its perfection on the level of technical progress, but on the deeper level of interpersonal relationships. These demand a mutual respect for the full spiritual dignity of the person. . . . Respect and love ought to be extended also to those who think or act differently than we do in social, political and even religious matters. In fact, the more deeply we come to understand their ways of thinking through such courtesy and love, the more easily will we be able to enter into dialogue with them. . . . The teaching of Christ even requires that we forgive injuries, and extends the law of love to include every enemy, according to the

6. Vatican Council II, *Gaudium et spes* (December 7, 1965), nn. 1–3.

command of the New Law: “You have heard that it was said: Thou shalt love thy neighbor and hate thy enemy. But I say to you: love your enemies, do good to those who hate you, and pray for those who persecute and calumniate you” (Matt. 5:43–44). . . . Since all men possess a rational soul and are created in God’s likeness, since they have the same nature and origin, have been redeemed by Christ and enjoy the same divine calling and destiny, the basic equality of all must receive increasingly greater recognition.⁷

Again, several key points can be found in these sections of *Gaudium et spes*. Though technology is, in a sense, shrinking the world and bringing all peoples closer together, real human closeness requires more than just technological connection. It requires that people acknowledge and value their shared human nature in each human being they encounter. This does not mean that we ignore our differences and disagreements. Instead, recognizing each individual’s worth helps each of us learn from our differences in order to gain a better understanding and appreciation both of human diversity and of the need for forgiveness. In fact, the call to affirm the presence of Christ in each person is so strong in the Christian tradition that a Christian is challenged to love and forgive even those who declare themselves his enemies and who intend to do him harm. This radical call to love all others—rooted in the actions of Christ during his own ministry, suffering, and execution—is the key element behind the Catholic Church’s advocacy on behalf of those threatened by eugenic policies, as well as its emphasis on avoiding any implementation of genetic technology that would selectively harm or eliminate human beings whom others judge to be unworthy of continuing to live as they are.

This radical stance of caring for all those who are in need, no matter their circumstances or their attitude toward the Catholic Church, was further institutionalized in 1985 by Pope St. John Paul II’s apostolic letter *Dolentium hominum*, which established the Pontifical Commission for the Apostolate of Health Care Workers (later, the Pontifical Council for Pastoral Assistance to Health Care):

The deep interest which the Church has always demonstrated for the world of the suffering is well known. In this for that matter, she has done nothing more than follow the very eloquent example of her Founder and Master. . . . In fact, over the course of the centuries the Church has felt strongly that service to the sick and suffering is an integral part of her mission, and not only has she encouraged among Christians the blossoming of various works of mercy, but she has also established many religious institutions within her with the specific aim to fostering, organizing, improving and increasing help to the sick. . . . In her approach to the sick and to the mystery of suffering, the Church is guided [by] a precise concept of the human person and of his destiny in God’s plan. She holds that medicine and therapeutic cures be directed not only to the good and the health of the body, but to the person as such who, in his body, is stricken by evil. In fact, illness and suffering are not experiences which concern only man’s physical substance, but man in his entirety and in his somatic-spiritual unity. For that matter, it is known how often the illness which is manifested in the body has its origins and its true cause in the recesses of the human psyche.⁸

7. Ibid., nn. 23, 28–29.

8. John Paul II, *Dolentium hominum* (February 11, 1985), nn. 1–2.

This new pontifical commission was to facilitate, from the institutional center of the Church, the fundamental goals all Catholics were to be pursuing in their own ways. If we are to love others as Christ did, then special attention had to be given to those who are suffering and in need. To achieve this goal as a Church required an institutional commitment to support health care. That commitment required supporting and enhancing healing that is not merely physiological but also mental and spiritual.

Hence, on both the individual and the institutional levels of the Church, healing can always be made available, even as a patient is dying. Attention to anxiety, depression, and pain can significantly benefit a person even when he is close to death. The overall goal of the Church in caring for those in need is to heal as Christ did—bringing another human being whatever wholeness and fulfillment are possible primarily through loving care, assisted by whatever technology can provide. This approach is consistent with evidence-based medicine, as it has been widely established that patients who feel connected, cared for, and supported do better no matter the medical technology employed.⁹

Developments in the Church's Vision in Light of Advances in Genetics and Genomics

What genetic research has uncovered over the past several decades is both how minute changes in our DNA can have profound effects on our overall health and welfare and how experiences in our everyday lives, psychological and physical, can greatly affect our biological functioning overall. How has the Church responded to such discoveries in terms of its understanding of human nature and the need to evaluate our rapidly developing biotechnology in light of how it might improve the health care the Church desires for all?

Among Church documents, *Dignitas personae* most directly addresses gene therapy:

For a moral evaluation the following distinctions need to be kept in mind. *Procedures used on somatic cells for strictly therapeutic purposes are in principle morally licit.* Such actions seek to restore the normal genetic configuration of the patient or to counter damage caused by genetic anomalies or those related to other pathologies. Given that gene therapy can involve significant risks for the patient, the ethical principle must be observed according to which, in order to proceed to a therapeutic intervention, it is necessary to establish beforehand that the person being treated will not be exposed to risks to his health or physical integrity which are excessive or disproportionate to the gravity of the pathology for which a cure is sought. The informed consent of the patient or his legitimate representative is also required.

The moral evaluation of *germ line cell therapy* is different. Whatever genetic modifications are effected on the germ cells of a person will be transmitted to any potential offspring. Because the risks connected to any genetic manipulation

9. For examples both in preventive and critical care medicine, see “Improved Outcomes Start with Patient Engagement,” HealthTrust, October 14, 2015, <http://healthtrustpg.com/>; and Judy E. Davidson et al, “Clinical Practice Guidelines for support of the Family in the Patient-Centered Intensive Care Unit: American College of Critical Care Medicine Task Force 2004–2005,” *Critical Care Medicine* 35.2 (February 2007): 605–622, doi: 10.1097/01.

are considerable and as yet not fully controllable, *in the present state of research, it is not morally permissible to act in a way that may cause possible harm to the resulting progeny. . . . The question of using genetic engineering for purposes other than medical treatment also calls for consideration.* Some have imagined the possibility of using techniques of genetic engineering to introduce alterations with the presumed aim of improving and strengthening the gene pool. Some of these proposals exhibit a certain dissatisfaction or even rejection of the value of the human being as a finite creature and person. Apart from technical difficulties and the real and potential risks involved, such manipulation would promote a eugenic mentality and would lead to indirect social stigma with regard to people who lack certain qualities, while privileging qualities that happen to be appreciated by a certain culture or society; such qualities do not constitute what is specifically human. This would be in contrast with the fundamental truth of the equality of all human beings which is expressed in the principle of justice, the violation of which, in the long run, would harm peaceful coexistence among individuals. Furthermore, one wonders who would be able to establish which modifications were to be held as positive and which not, or what limits should be placed on individual requests for improvement since it would be materially impossible to fulfil the wishes of every single person. Any conceivable response to these questions would, however, derive from arbitrary and questionable criteria. All of this leads to the conclusion that the prospect of such an intervention would end sooner or later by harming the common good, by favouring the will of some over the freedom of others.¹⁰

This quotation highlights several important aspects. The benefits of a procedure must be proportionately greater than the risks it poses to health or physical integrity, so one should not use genetic interventions for cosmetic purposes. Since germline interventions present risks to future generations, they require a level of safety that has not been demonstrated yet and must not involve procedures, such as IVF, that destroy human lives. However, therapeutic modifications to germline cells might not be ruled out if adequately safe procedures and outcomes can be obtained. Finally, the use of genetics to enhance or change human nature to create supposedly improved beings is rejected on the basis of the same reasoning that inspired the Church to resist the eugenics movement of the twentieth century. By purposefully attempting to create individuals who are considered better and more valuable than others, such interventions that foster a fundamental discrepancy in the valuation of different human beings violate the Christian vision of the primacy of the equality of all human lives and harm the common good of human society. Considering the horrendous human destruction to which such attitudes have led and continue to lead the human family, the Church is staunchly opposed to the use of any technology that promotes such attitudes. Instead, the Church reiterates its emphasis on caring for people where and as they are.

Even with the considerable attention given to genetic interventions when *Dignitas personae* was written less than ten years ago, recent advances in genetics, epigenetics, and genetic manipulation now appear to blur some of the traditional distinctions observed in the document, such as therapy versus enhancement. Another

10. Congregation for the Doctrine of the Faith, Instruction *Dignitas personae*, On Certain Bioethics Questions (September 8, 2008), nn. 26–27, original emphasis.

revision may be in order to better articulate the Catholic position on human genome editing. In addition, our complex balance of genes and gene expression may require trade-offs, leading to our final issue: how will the vision of the primacy of each human life be useful, even crucial, in the ongoing global discussion of human genome editing?

The Catholic Contribution to Current Challenges in Human Genome Editing

Despite the stain eugenics left on the twentieth century, new technological advances in genome editing may once again be increasing interest in some forms of eugenics. Current proposals run the gamut, from correcting genetic flaws in certain individuals and their offspring to improving the human species through genetic manipulation and cybernetics, as transhumanists propose.¹¹

In the final analysis, though, contemporary ideas for genetic improvement of the human species are not much different from Galton's proposals. The demarcation between what should be considered corrections of human genetic flaws and what would actually be attempts to improve human beings beyond their present capacities is not easily delineated. Currently, no mainstream proposals tout a specific ideal human type as the target of genetic engineering, in part because knowledge of genetics and evolution has revealed the importance of diversity in the fitness of any species. Still, genetic interventions first implemented under one set of conditions as a therapy (e.g., stimulating the growth of new blood vessels or muscle tissue to combat disease) might appeal to people in other situations as genetic enhancements (e.g., stimulating the growth of new blood vessels or muscle tissue to enhance athletic performance). As ethicist Eric Juengst recognized in the 1990s, "pretty much any enhancement we can envision could be packaged as a treatment."¹²

Still, it is argued that some genetic enhancements would be truly beneficial for human beings. Academic and popular literature are full of proposals for enhanced immune systems, better memories, increased intelligence, a heightened sense of empathy, delay or prevention of the aging process, and even simply increased height.¹³

Both Galton and Plato shared the goal of selectively increasing the intelligence and health of certain offspring. Their methodologies paralleled the methods of animal husbandry. Men and women exhibiting certain culturally desired traits would be paired, and their issue would undergo similar selective breeding. The process would be repeated until the target population exhibited greater capacity for the chosen characteristics.

11. For example, see the work of transhumanist activist Zoltan Istvan, available at <http://www.zoltanistvan.com/>.

12. Vincent Kiernan, "Cosmetic Uses of Genetic Engineering May Soon Be a Reality," *Chronicle of Higher Education*, October 3, 1997, A18.

13. In addition to those of the transhumanists, examples of arguments for enhancement genetics can be found in the following: Lee M. Silver, *Remaking Eden: How Genetic Engineering and Cloning Will Transform the American Family* (New York: Avon/Eos, 1998); and Julie Gage Palmer and LeRoy Walters, *Ethics of Human Gene Therapy* (New York: Oxford University Press, 1997).

Recent advances in molecular genetics promise to greatly accelerate this process of selective enhancement. Instead of requiring several generations of controlled mating, desired enhancements could be achieved more quickly and without regulating mate selection. In fact, current technologies would allow individuals to change multiple genetic targets in just one intervention. This situation further complicates the task of distinguishing between therapy and enhancement.

For example, after analyzing reports of individual resistance to multiple exposures to HIV, scientists concluded that certain people have genes that make it much more difficult for HIV to infect their T cells (cells of the immune system that the virus attacks).¹⁴ Using this knowledge and some new technology, researchers have fashioned a potential treatment for patients with HIV/AIDS by engineering some of their T cells to take on this particular genetic characteristic in hopes of stocking their immune systems with HIV resistant T cells.¹⁵ If the clinical trials proceed as hoped, a treatment that cures AIDS patients of their HIV infections may finally be widely available. If and when that happens, will there not be calls for the treatment to be made available as a preventive measure for health care professionals who work closely with AIDS patients? What about the spouses of HIV-positive individuals or patients who require frequent blood products? How will we develop health care policies that say who should get this treatment and who should not, since anyone who risks exposure could benefit from becoming immune to HIV? At what point would this therapy become an enhancement, and who would be responsible for making such a decision?

Since vaccination is already a mainstay of modern medicine and since HIV/AIDS is so devastating, one could argue that a genetic intervention to prevent infection should be considered a gene therapy rather than a genetic enhancement. Conversely, one might argue that the people who would receive the treatment are not ill and do not require it to avoid the disease. In addition, it is natural for different people in a given population to have different levels of genetic resistance to diseases. Hence, genetic interventions to prevent HIV infection must be considered an enhancement. This debate is mentioned not to suggest a resolution to the problem of HIV infection, but to further illuminate the problems encountered when we apply the distinction between therapy and enhancement to human genetic interventions.

This difficulty of distinguishing between what could be considered therapeutic genetic interventions and what would have to be recognized as genetic engineering

14. Cedric Blanpain et al., "Multiple Charged and Aromatic Residues in CCR5 Amino-terminal Domain Are Involved in High Affinity Binding of Both Chemokines and HIV-1 Env Protein," *Journal of Biological Chemistry* 274 (December 3, 1999): 34719–34727; Chia-Suei Hung et al., "Relationship between Productive HIV-1 Infection of Macrophages and CCR5 Utilization," *Virology* 264.2 (25 November 1999): 278–288; and Leondios G. Kostrikis et al., "A Polymorphism in the Regulatory Region of the CC-Chemokine Receptor 5 Gene Influences Perinatal Transmission of Human Immunodeficiency Virus Type 1 to African-American Infants," *Journal of Virology* 73 (December 1999): 10264–10271.

15. For example, see University of Pennsylvania, "A Phase I Study of T-Cells Genetically Modified at the CCR5 Gene by Zinc Finger Nucleases SB-728mR in HIV-Infected Patients," *ClinicalTrials.gov*, identifier NCB02388594, last verified May 2017, <https://clinicaltrials.gov/ct2/show/NCT02388594>.

to enhance human nature is only part of the current public discussion. There are many other ethical and public policy questions concerning the possible application of genome editing in human beings. The resolution of all these issues, however, depends, at least in part, on addressing this distinction between genetic enhancement and genetic therapy, because their differences rest on the definitions of health and disease, which are at the foundation of medicine.

Whether a genetic intervention will be considered therapy or enhancement depends on how members of society and the medical profession interpret the goals of the intervention and the condition of the patient. For example, the same genetic intervention for increasing intelligence could be viewed as therapy when applied to an individual evaluated as mentally deficient or as enhancement when done to an individual of average intelligence. Hence, answers to the question of whether a genetic intervention should be considered therapy or enhancement lose their relevance if there is disagreement over the definitions of health and disease.

Since health is often delineated by reference to the normal functioning of a person, in whole or in part, the key question is, how should normal human physiology and behavior be delineated? Any thorough answer to this question will have to include a response to the challenges that advances in genetics pose to existing concepts of normal human functioning.¹⁶

A recent finding in genetic research will help elucidate this point. Over the past few decades, medical researchers have followed a group of people in Ecuador who are related and share a genetic mutation that results in a metabolic condition called Laron syndrome, which significantly reduces their growth (most are less than four feet six inches tall) and causes other physiological challenges.¹⁷ This group was carefully studied by researchers to both find the cause of their condition and possibly develop a treatment for it. The researchers discovered a single genetic change in the human growth hormone receptor (*GHR*) gene, which results in a growth hormone system deficiency that causes their short stature as well as other clinical features.

In addition to their diminutive stature and distinct facial features, the Laron group also displayed some striking positive characteristics, most surprisingly a total absence of both malignant cancer and type 2 diabetes. According to an article published in *Science Translational Medicine*, not one person in the group exhibited type 2 diabetes or malignant tumors, whereas members of a local control group had a

16. Philip J. Boyle, "Shaping Priorities in Genetic Medicine," *Hastings Center Report* 25.3 (May–June 1995): S2–S8; and William R. Clark, *The New Healers: the Promise and Problems of Molecular Medicine in the Twenty-First Century* (New York: Oxford University Press, 1997). A brief, more personal perspective offered by a clinical geneticist that can be found among other contributions is: John M. Opitz, "The Geneticization of Western Civilization: Blessing or Bane?," in *Controlling Our Destinies: The Human Genome Project from Historical, Philosophical, Social, and Ethical Perspectives*, ed. Phillip R. Sloan (Notre Dame, Ind.: Notre Dame Press, 2000).

17. Gary Taubes, "Rare Form of Dwarfism Protects against Cancer," *Discover Magazine* (March 27, 2013), <http://discovermagazine.com/2013/april/19-double-edged-genes>.

5 percent rate of type 2 diabetes and a 17 percent rate of cancer.¹⁸ This amazing group of people has revealed a disconcerting reality that may become much more common as genomic research expands around the globe: apparently simple genetic differences can result in surprising physiological conditions, which both provide health benefits and cause illness susceptibilities in the people who have them.

Insights from similar research can reveal new complexities of current therapies and treatments. For instance, children who are expected to be significantly shorter than average and who do not have a mutation that disables their *GHR* gene are often offered a growth hormone treatment to increase the height they will reach as adults. One risk of this treatment is that the children will be six times more likely to develop type 2 diabetes than if they had not received the treatment. A study published in 2015, using insights gained from research on the metabolism of persons with Laron syndrome, provides new insight into why this increased risk exists, which may help doctors and parents balance the benefits and harms of growth hormone therapy for children.¹⁹

This discovery of the role of the human *GHR* gene reveals an intricate balance between health and disease that is intrinsic to the fundamental genetic fabric of human nature. Maintaining this equilibrium will become a greater challenge for patients, parents, and physicians as research reveals more of this complex trade-off between health and disease. Even in the midst of this challenge, biotechnological advances such as genome editing will offer people the opportunity to manipulate their own or their children's genomes and shift the balance of health benefits and risks. In the case of *GHR* mutations, parents could decide that they want to use genome editing to create a Laron-like mutation in a child's *GHR* to reduce the chance of contracting cancer or type 2 diabetes when the child's diet, environment, and lifestyle would normally create a relatively high risk for these illnesses. That child would then have to balance that health benefits with the social stigma of unusually short stature and different facial features. Would such decisions be best left to parents on a case-by-case basis, or should society have some say in them? How do we begin to deliberate about such issues? As with eugenics, some historical perspective helps to clarify the advantages and disadvantages of various options.

One decision-making approach that has been widely embraced around the world in the past several decades allows a patient, parents, or legal guardian to make whatever treatment decisions they think are best as long as the treatments are affordable. While this method has certain appealing features—in particular, the simplicity of allowing people to make their own choices for themselves and their children—recent global experience with the use of prenatal diagnostic technologies for sex-selective abortions gives clear evidence of the social problems that can arise from this approach. First, it is widely acknowledged that sex selection has significantly unbalanced the

18. Jaime Guevara-Aguirre et al., "Growth Hormone Receptor Deficiency Is Associated with a Major Reduction in Pro-Aging Signaling, Cancer, and Diabetes in Humans," *Science Translational Medicine* 70.3 (February 16, 2011): 13.

19. Jaime Guevara-Aguirre et al., "GH Receptor Deficiency in Ecuadorian Adults Is Associated with Obesity and Enhanced Insulin Sensitivity," *Journal of Clinical Endocrinology and Metabolism* 100.7 (July 2015): 2589–2596.

male–female ratios in China and India, the two most populous nations in the world.²⁰ However, it is probably much less well known that this problem is also present in other nations around the world and in some populations in the United States.²¹ While this situation raises major societal, ethical, and policy issues regarding the use of prenatal diagnosis for sex selection, it also indicates the need to develop ethical and policy approaches to human genome editing that can balance individual and community goods and goals, especially when they conflict.

From this brief review of the many ethical challenges that new genome editing technology presents to the world, we can revisit the question posed at the beginning of this essay: how will we know when we are ready to apply genome editing technology to human beings in a way that will provide broad benefits and avoid harms? From a pragmatic and logistical perspective, we could say that we will have a good idea that we are ready when we can address the issues of who should be genetically modified and to what extent and when we are able to integrate both individual and societal desires and concerns into our framework for implementation. While this statement may sound straightforward, it contains major assumptions that cannot be easily or readily addressed. These concerns can be reduced to the question of how to integrate the often contrary or conflicting desires and concerns of both individuals and communities in a way that will engender extensive public support for the proposed implementation of human genome editing—even if the public chooses not to allow human genome editing at all.

One potential contribution of the Catholic Church is its emphasis on the primacy of all human lives, which alleviates the tension and controversy over deciding whose life is worthwhile, that is, worthy of continuance and care. From the Catholic perspective, everyone is worthy, and the Church clearly includes all human beings from the time of their organismal initiation, that is, almost always conception, to the time of their organismal dissolution, or death. In other words, the focus should be on figuring out how best to care for each individual. Instead of establishing arbitrary criteria, access to scarce resources should be given first to those who need them the most.

Accepting this Catholic standard of universal care does not necessarily clarify what kind of help we should offer to whom and when. Here again, discerning the appropriate genomic intervention requires a complex yet balanced understanding of individual, community, and species health. This, in turn, demands a comprehensive, integrated, and dynamic framework for understanding human nature and health in order to keep up with both the rapid pace of scientific discovery and the diverse global responses to it. Such heuristic strategies are an essential aspect of the Catholic moral tradition.

This type of heuristic framework can be contrasted with competing paradigms whose narrower, reductionist strategies often prioritize one set of goods and knowledge over all others. For example, less comprehensive and integrative heuristic approaches

20. Anna Higgins, “Sex-Selection Abortion: the Real War on Women,” American Reports Series, Charlotte Lozier Institute, April 13, 2016, <https://lozierinstitute.org/sex-selection-abortion-the-real-war-on-women>.

21. *Ibid.*, 3.

may base their evaluations of good or bad uses of a new biotechnology on individual autonomy, science, a technological imperative, economic and financial issues, or even a particular traditional view of human nature grounded in an outdated understanding of biology. Regardless of what good is given precedence, these narrow frameworks cannot effectively integrate our rapidly expanding scientific and technical knowledge with the many other types of knowledge that inform our understanding of human nature and our shared goal of becoming healthier both individually and communally.

In earlier works, I have explained at length the advantages of employing a more dynamic and integrative framework in our evaluation of technologies such as human genome editing,²² so here I will only summarize the elements of this paradigm that pertain to the best use of biotechnologies in the twenty-first century.

To truly understand who we are as a species and who we aspire to become, we need to reflect on all the different fields of inquiry that inform our understanding of ourselves, such as philosophy, theology, law, economics, history, sociology, psychology, literature, the fine arts, political science, and the natural sciences. This broad scope of reflection will need to be balanced as well as inclusive. In other words, each discipline should be approached as a relatively equal partner in this critical effort, since the consequences of employing powerful biotechnologies will be felt in all dimensions of human existence. This comprehensive and integrated approach is deeply rooted in the Catholic intellectual tradition, as exemplified by Pope Benedict XVI in his encyclical letter *Caritas in veritate*:

This means that moral evaluation and scientific research must go hand in hand, and that charity must animate them in a harmonious interdisciplinary whole, marked by unity and distinction. The Church's social doctrine, which has "*an important interdisciplinary dimension*," can exercise, in this perspective, a function of extraordinary effectiveness. It allows faith, theology, metaphysics and science to come together in a collaborative effort in the service of humanity. It is here above all that the Church's social doctrine displays its dimension of wisdom. Paul VI had seen clearly that among the causes of underdevelopment there is a lack of wisdom and reflection, a lack of thinking capable of formulating a guiding synthesis, for which "a clear vision of all economic, social, cultural and spiritual aspects" is required. The excessive segmentation of knowledge, the rejection of metaphysics by the human sciences, the difficulties encountered by dialogue between science and theology are damaging not only to the development of knowledge, but also to the development of peoples, because these things make it harder to see the integral good of man in its various dimensions. The "broadening [of] our concept of reason and its application" is indispensable if we are to succeed in adequately weighing all the elements involved in the question of development and in the solution of socio-economic problems.²³

We see again in this encyclical the theme of the unity of creation and the ways in which we can better understand it, and our human fulfillment within it, by bringing together the various ways that we know reality. As we work together to

22. Kevin T. FitzGerald and Charmaine Royal, "The Need for a Dynamic and Integrative Vision of the Human for the Ethics of Genetics," in *Genetics, Theology, and Ethics*, ed. Lisa Sowle Cahill (New York: The Crossroad, 2005), 79.

23. Benedict XVI, *Caritas in veritate* (June 29, 2009), n. 31, original emphasis.

bring about our fulfillment within creation, both as individuals and as a species, our integrated knowledge can lead to actions that incorporate the different dimensions of our lives into a common good for all people. This argument for the integration of knowledge and action for the common good is reemphasized by Pope Francis in his apostolic exhortation *Evangelii gaudium*, On the Proclamation of the Gospel in Today's World. Looking particularly at the section titled "Dialogue between Faith, Reason and Science," we find,

Dialogue between science and faith also belongs to the work of evangelization at the service of peace. Whereas positivism and scientism "refuse to admit the validity of forms of knowledge other than those of the positive sciences," the Church proposes another path, which calls for a synthesis between the responsible use of methods proper to the empirical sciences and other areas of knowledge such as philosophy, theology, as well as faith itself, which elevates us to the mystery transcending nature and human intelligence. Faith is not fearful of reason; on the contrary, it seeks and trusts reason, since "the light of reason and the light of faith both come from God" and cannot contradict each other. Evangelization is attentive to scientific advances and wishes to shed on them the light of faith and the natural law so that they will remain respectful of the centrality and supreme value of the human person at every stage of life. All of society can be enriched thanks to this dialogue, which opens up new horizons for thought and expands the possibilities of reason. This too is a path of harmony and peace.²⁴

Francis further develops these points in his much-discussed encyclical letter *Laudato si'*, On Care for Our Common Home:

Certainly, these issues require constant attention and a concern for their ethical implications. A broad, responsible scientific and social debate needs to take place, one capable of considering all the available information and of calling things by their name. It sometimes happens that complete information is not put on the table; a selection is made on the basis of particular interests, be they politico-economic or ideological. This makes it difficult to reach a balanced and prudent judgement on different questions, one which takes into account all the pertinent variables. Discussions are needed in which all those directly or indirectly affected (farmers, consumers, civil authorities, scientists, seed producers, people living near fumigated fields, and others) can make known their problems and concerns, and have access to adequate and reliable information in order to make decisions for the common good, present and future. This is a complex environmental issue; it calls for a comprehensive approach which would require, at the very least, greater efforts to finance various lines of independent, interdisciplinary research capable of shedding new light on the problem.²⁵

In spite of these calls for integrated research and development that will serve the common good, some individuals will still be suspicious of any attempt to integrate religious perspectives with scientific knowledge and technological development. This mistrust is often given credence in our contemporary academic world by philosophical

24. Francis, *Evangelii gaudium* (November 24, 2013), n. 242.

25. Francis, *Laudato si'* (May 24, 2015), n. 135.

skepticism toward any possibility of codifying a comprehensive world view and by historical instances when religion was used as an excuse for one group's attempts to dominate others. While multiple examples certainly support both of these perspectives, the eugenics movement provides numerous counterexamples that show the need for a comprehensive, integrated, and dynamic framework. In addition, the Catholic perspective also emphasizes the fundamental interdependence and interrelationality of our human condition, and hence argues for the need to subordinate technological development to the good of all peoples, especially those who are most vulnerable to technology's harmful applications.

Critics respond that these Catholic arguments assume the relevance of including religious experience in public discourse. Although often raised, this criticism is readily addressed on strictly secular grounds, because religions perspectives must be included in any framework that would adequately undergird a global deliberation. I have presented one such argument in previous publications.²⁶ Its key elements are that (1) flawed epistemological reasoning claims that scientific knowledge is the only type that should be incorporated into a framework that judges the proper use of biotechnologies, and (2) we need a broad and rich description of human nature and experience, because genetic interventions can and will affect human beings on all levels of their existence. From these two points alone, one can establish the appropriateness of including wisdom from religious traditions, along with many other types of knowledge, in any system of global deliberations.

Although academic institutions of higher education should be promoted as one arena where this broad and balanced integration of experience, insight, and knowledge can be fostered, the extent of public engagement that will be required to develop a truly comprehensive, integrative, and dynamic framework will necessarily involve nations and international organizations in order to obtain as broad a spectrum of public representation as possible. This extensive public engagement will also draw attention to the marginalized and outcast, whose voices are often not heard in the clamor of the public square. Their input will be particularly crucial in weaving the rich tapestry of human understanding that will be required to ensure that global deliberation will benefit both individuals in need and humankind as a whole. This intentional inclusion of the marginalized also conforms to the publicly supported fundamental goal of biomedical research to bring new and better treatments and care to those most in need. Similar arguments have been made publicly by scientists and scholars involved in the development of genome editing.²⁷

This kind of public engagement resonates with the emphasis Francis has placed on the Catholic mission of caring for those most in need. The Pope's analysis identifies the benefits all people will receive from seeing the richness of the human condition through the experiences of the poor and the afflicted:

26. FitzGerald, "The Need for a Dynamic and Integrative Vision," in Cahill, *Genetics, Theology and Ethics*, 79.

27. David Baltimore et al., "A Prudent Path Forward for Genomic Engineering and Germline Gene Modification," *Science* 348.6230 (April 3, 2015): 37.

For the Church, the option for the poor is primarily a theological category rather than a cultural, sociological, political or philosophical one. God shows the poor “his first mercy.” . . . We need to let ourselves be evangelized by them. The new evangelization is an invitation to acknowledge the saving power at work in their lives and to put them at the centre of the Church’s pilgrim way. We are called to find Christ in them, to lend our voice to their causes, but also to be their friends, to listen to them, to speak for them and to embrace the mysterious wisdom which God wishes to share with us through them.²⁸

Though Francis proclaims the theological basis for the Church’s strong stance on giving preference to the needs of the poor, he also intimates that the insights into our human condition, which are illustrated in the experiences of the poor, are available for all to see. These are insights that all of us would miss if we choose to ignore or deny the value of their lives and experiences.

It is clear that we need a broad public discussion of human genome editing and the empowerment of as many people as possible to join it. People’s aspirations are even more diverse than their physiologies, and we need to know as much as possible about these differences to know which uses of human genome editing have the best chance of bringing an individual, a community, and our entire human family the kind of fulfilling lives we all want and deserve.

The Catholic Church has much to contribute as a facilitator of this global public engagement. It has its long and extensive history in health care, a powerful vision of the fundamental value of each human being, and the need to care for human beings in all dimensions and stages of life. In addition, the Church has traditionally promoted scientific inquiry and has worked to integrate technological advances in ways that foster the common good.

Through both its interaction with science and technology and its desire to fulfill each human life, the Church has developed an intellectual tradition that continually pursues a comprehensive, integrative, and dynamic understanding of the human condition—an understanding that is accessible to all even as it is expressed most richly in terms of its own religious concepts and experience. This rich understanding of the human condition can be applied in a global context to contribute to the discussion of how all peoples might determine the best applications of human genome editing for the various needs and aspirations of our current age.

Hence, the future is filled with both opportunities and obligations for the Catholic Church to continue and even expand its clearly stated goal of engaging with the world in a way that enhances the human condition for each person in this life and, we hope and believe, in the next. Human genome editing is just the latest technology humankind has developed with its God-given abilities. The Catholic Church needs to address it with all the values, skills, and wisdom the Church has developed from its past, to help ensure that this technology and all future ones will be used for the betterment of all, especially the poor and the most vulnerable.

28. Francis, *Evangelii gaudium*, n. 198.