

WHAT'S A CATHOLIC TO THINK?

On April 14, 2003, leaders from the international consortium of genome sequencing centers announced that the 3.1 billion base pairs of human DNA had been sequenced. This was an astonishing achievement, testifying to the great capacity of human inquiry, ingenuity, and intelligence. Even more important, this accomplishment provides incomparable insight into the intricacy and the wonder of the human organism. It leaves one with a profound sense of awe, humility, and respect before this marvel of God's creation.

The sequencing of the human genome is also remarkable for the potential improvements it will engender in medical care, thereby enhancing human well-being. The new knowledge it affords will reveal the causes and pathways of a host of diseases with genetic linkages that inflict untold suffering upon humanity. In turn, this will provide numerous opportunities for more effective prevention, diagnosis, and treatment of many of these diseases—whether through genetic testing, targeting drugs to an individual's particular genetic makeup (pharmacogenetics), or correcting the deleterious effects of a genetic mutation through gene therapy.

At the same time, however, the knowledge

*A Genomics
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gained from the sequencing of the human genome, and the various technologies that have been and will be derived from this knowledge, can be used in ways that negatively impact individuals and society at large. The challenge for Catholics and all others who will undoubtedly be affected by this newfound power to control and manipulate the human genome will be to harness the promise and, as much as possible, avoid the perils.

Given the potential for both good and harm, how might Catholics think about genomic advances in their development and multiple applications? Over the past year, a group of 16 theologians and ethicists, convened by the Catholic Health Association of the United States (see **Box**, p. 24), reflected on this question in light of Scripture, tradition, reason, and experience. The reflection developed into a "theological vision" for a Catholic engagement with genomics, intended primarily for Catholic health care providers, but surely applicable to all within the Catholic community. Although limited in that it does not offer ready-made solutions to the many issues that accompany genomics, the vision does provide a perspective from which to view, understand, and assess human endeavors in genomics and the use of genomic technologies such as genetic testing, pharmacogenetics, or, eventually, gene therapy. What follows are key elements of that vision.

SHOULD WE PURSUE GENOMICS?

Like society as a whole, the Catholic community has mixed reactions to genomics. Some believe we should embrace it for the promise it holds, whereas others think we should avoid any involvement in it because, among other things, it implicates us in "playing God." Although there are legitimate concerns expressed in the "playing God" metaphor, our engagement with genomics can be another way in which we *image* God, that



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is, participate in the unfolding of God's creation and continue God's healing work in the world. As human beings endowed with intelligence and creativity, we have been called to unlock the possibilities of God's creation and are not precluded from doing so by our religious beliefs. The Second Vatican Council says as much in discussing humanity's creative role in nature: "[I]t is clear that men [sic] are not deterred by the Christian message from building up the world. . . . [T]hey are, rather, more stringently bound to do these very things."¹

With regard to this exercise of our creativity, we must be mindful of two caveats. First, we are finite creatures who sometimes use our creative powers to pursue unattainable ends. Elements of this are already manifest in the misguided desires of some who look to genomics as a way in which

we can overcome the limitations imposed on us by our finitude. These aspirations are understandable. However, the maddening reality we must accept is that we can never fully overcome ourselves. Our fate is that we must live with disease, disability, suffering, and countless other limits. This is what it means to be creature and not God. Although we can and should strive to overcome human limitations through our ability to give them meaning, a complete transcendence of them through technological means will never be possible. Nor will the reduction of disease, disability, and suffering by themselves bring about the fullness of happiness and human flourishing. This is ultimately God's gracious gift beyond human history. Viewing human endeavors in genomics against the backdrop of our finitude can help us temper unrealistic expectations and use our creativity more constructively.

Second, we are sinful creatures who do not always use our creative powers to promote God's creation and human flourishing. From the beginning, we have abused our capacities, especially our freedom, to pursue ends that harm and even destroy our relationships with ourselves, others, God, and creation. Pride, egocentrism, greed, ambition, and other false gods tend to distort the ends that are most fitting for us to pursue. The phenomenon of sin is an ever-present reality and danger in the attempt to achieve a more complete understanding of the human genome. Yet sin does not have the last word. Where sin abounds, grace abounds even more. Grace, God's free and unmerited gift of God's self that enables humans to share in the divine life, is also ever-present and a supremely more potent force. By responding to grace, we can minimize the effects of sin bound up in hubris and the desire to master creation, and direct human endeavors in genomics toward ends that contribute to human flourishing and promote truly human values.

With these caveats in mind, we must now turn to the most critical moral question: "How do we know when our engagement with genomics is an appropriate use of our creativity?" The fundamental criterion for answering this is whether genomics serves persons integrally and adequately considered. If genomics is not pursued with the primary motive of serving humanity, it can easily degenerate into an enterprise that ultimately violates people, especially the neediest and weakest, and undermines the common good. This moral criterion for evaluating scientific inquiry was explicitly affirmed by the Second Vatican Council and has been reiterated in several magisterial statements since then. For instance, *Donum*

Shapers of the Genomics "Vision"

The theologians and ethicists convened by the Catholic Health Association to help shape "A Catholic Vision toward Genomic Advances," from which this article was adapted, were:

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Vitae states that "science and technology require, for their own intrinsic meaning, an unconditional respect for the fundamental criteria of the moral law: that is to say, they must be at the service of the human person, of his [sic] inalienable rights, and his [sic] true and integral good according to the design and will of God."² Underlying this moral criterion is a particular theological anthropology that views the human person as a multifaceted entity who is at once physical and material, relational and social, creative and spiritual, morally free and responsible. These dimensions are interconnected and interwoven to form a complex synthesis that constitutes the human person integrally and adequately considered.

HOW DOES GENOMICS SERVE PEOPLE?

Having briefly outlined the evaluative moral criterion, we must now ponder how genomics serves persons integrally and adequately considered. This is difficult to specify. However, what we can say is that genomics does this when it respects the totality of the person and improves the person's overall condition, enabling him or her to more fully participate in the various dimensions of life and better pursue the purposes of life, which are love of God and love of neighbor. It is only when doing this that genomics can truly serve people and contribute in important ways to human flourishing.

Admittedly, this is still somewhat vague. Fortunately, we are equipped with some guiding principles rooted in a theological understanding of the person that can help us further discern how genomics serves people. They are *human dignity*, *relationality*, and *solidarity with the disadvantaged*.

Human Dignity All human beings, regardless of any possible defining capacities or characteristics, have an inalienable and inviolable dignity from conception until death. This status derives from their having been created out of divine love in God's own image and likeness for communion with God. The dignity that extends to all people requires the utmost reverence and respect in the ways in which we relate to them.

Genomics has the potential to further the dignity of individuals by, for example, preventing, reducing, or eliminating disease and disability and the suffering associated with them, thereby improving their quality of life so that they might better pursue the purposes of life. However, the inherent dignity of human persons suggests, among other things, that we do not prevent so-called "imperfect" human beings from being born; base the worth of people on the quality of

their genomes or some idealized genome; diminish the value of those afflicted with genetic disease; subordinate the good of individuals and the community to profit or reputation; or make the benefits of genomics available to some but not to others. As we pursue advances in genomics, we must resist the temptation to engage in activities and practices that could violate the dignity of our fellow human beings.

Relationality Human beings are made in the image of a triune God whose very nature is to be in relationship. Consequently, we are fundamentally directed toward others and God, and we achieve our fulfillment in and through these relationships. Because of this interrelatedness, we have a responsibility to respect the dignity and promote the flourishing of individuals and to advance the common good.

Genomics has the potential to enhance our relationality, as well as the common good, by, for example, preventing potential harm from coming to at-risk family members by sharing genetic information with them, or by better positioning couples to make reproductive decisions when one or both individuals are carriers of a severe genetic disorder. However, our inherent relationality suggests, among other things, that we do not use genetic information in a way that causes a rift between family members or that poses a threat to unborn life; disregard the possible impact of genetic disease on a future human being, as well as on existing family members; relegate some individuals to the fringes of society because of genetic disease; engage in practices of a eugenic nature, thereby creating a society free of individuals with "unacceptable" genetic diseases; allow genetic information to be used for employment and insurance discrimination; expend a disproportionate amount of money and time on genomics research without attending to basic health needs; or put self-interest ahead of community health needs in the selection of genomic-related service lines. As we pursue advances in genomics, we must ensure that we do not fundamentally harm the social nature of individuals and damage their relationships with others or weaken their responsibilities to one another and for the common good.

Solidarity with the Disadvantaged Our fundamental relationality implies an attitude and virtue of *solidarity*, a strong and ongoing commitment to the common good—the good of all and of each individual. Related to this is a special obligation to those who are disadvantaged—the poor, the uninsured, children and the unborn, the elderly, the disabled, and racial minorities, among others. We

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must ensure that their dignity is being respected, their basic needs are being met, and they are fully integrated into the community so they are able to flourish. In addition, we are called to evaluate social and other structures from the perspective of those who are at the margins of society and then work for the transformation of those structures, policies, and practices.

Genomics has the potential to improve the health status and alleviate some of the suffering of the disadvantaged and, thereby, contribute to their human flourishing in numerous ways, such as by increasing society's capacity to provide cost-effective primary care and increasing its ability to prevent, diagnose, and treat diseases with genetic components. However, our commitment to solidarity suggests, among other things, that we do not distribute the goods of genomics unfairly, thereby excluding the disadvantaged from sharing in these benefits; exploit vulnerable members of society by imposing upon them a disproportionate share of the burdens of genomics research and its applications; formulate public policies and practices concerning genomics without considering the perspective and interests of the marginalized and powerless; or exacerbate grave injustices in the current health care system by diverting scarce resources away from the more basic services needed by the millions of uninsured and underinsured members of our society. As we pursue advances in genomics, we must do so with a keen awareness of the social situation of the disadvantaged and with a firm resolve to give voice to the voiceless and reduce injustices in our health care system so that the benefits of genomics will be distributed equitably.

THE CATHOLIC COMMUNITY'S TASK

In the years ahead, there will undoubtedly be remarkable advances in our further understanding of the human genome and in the development and use of a variety of genomic advances. It is quite likely that these advances will significantly reshape both medicine and health care delivery, having a profound impact on individuals and society. Like all scientific developments, these advances have the potential for enormous benefit as well as harm. Despite the potential for harm, the Catholic community can and should become involved in genomics because of the promise it holds and the opportunities it affords to participate in God's creative and healing work in the world. By becoming involved, and only by becoming involved, Catholics, if they are true to their core values and beliefs, can demonstrate the use of human creativity in this area in ways that

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In addition, the Catholic community—schools, universities, parishes, and health care and social service providers—can play a significant role in helping to transform a culture that is somewhat at odds with a more authentic and holistic understanding of the human person and the purposes of life. The values that dominate American society often are not congruent with the values of human dignity and the sacredness of life, relationality and the common good, solidarity with the disadvantaged, and other matters of social justice.

The first challenge for the Catholic community is to foster an internal culture that embodies these values. This will require focused and sustained educational endeavors. Then, together with like-minded others, it may be possible to effect some change in the broader American culture so that these fundamental human values are more broadly recognized and embodied, thereby obviating some of the perils that could be brought on by genomic advances.

Finally, the Catholic community must work together and with others to protect the disadvantaged and act as advocates on their behalf so as to ensure that the basic needs of all people are met and the benefits of genomic advances are distributed equitably. For this to happen, the various ministries of the church will need to engage in coordinated and sustained efforts so that the collective weight of these ministries can be leveraged to bring about the necessary change in social attitudes, practices, policies, and structures essential for ethical integration of genomics into medicine and society. In imitation of Jesus who challenged the social attitudes and practices of his day when they alienated people from the community and from their own selves, the Catholic community must give voice to the voiceless so that genomic advances become for them an opportunity for flourishing, not further disadvantage. □

NOTES

1. Vatican Council II, *Gaudium et Spes*, 1965, section 34, available at www.vatican.va/archive/hist_councils/ii_vatican_council/documents/vat-ii_cons_19651207_gaudium-et-spes_en.html.
2. Congregation for the Doctrine of the Faith, *Donum Vitae*, 1987, section 2, available at www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_19870222_respect-for-human-life_en.html.