Justice and Genetics: Whose Holy Grail?

GENOMICS THREATENS TO WIDEN THE GAP BETWEEN THE WEST AND DEVELOPING NATIONS

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A FEW YEARS AGO, I taught an undergraduate course in medical ethics in which one of the students was a young woman from Uganda. One day, the class became engaged in a heated debate about the right to terminate treatment. The discussion centered on a case involving a teenaged boy who had end-stage cystic fibrosis. The boy's mother argued vehemently for continued ventilator support, whereas the boy himself begged the medical team to let him die. The class disagreed passionately about who should be allowed to make the decision, the parent or the teenager.

I noticed that my Ugandan student (who had been fairly quiet in the class until then) was shaking her head, as if in amazement. When I asked her what she was thinking, she said, "In my country, if you had the treatment, you'd use it! How amazing it is to be in a country where the ethical debates are all about when to say too much is too much, and not about why some people have no treatment at all."

In *Bioethics and the Common Good*, her 2004 Pere Marquette Theology Lecture at Marquette University, Milwaukee, Lisa Sowle Cahill argues that what happened in my classroom that day has happened gradually in the field of Christian bioethics over the latter part of the 20th century.[1] As it has faced the challenges of globalization, bioethics has begun to shift its lens away from a narrow concern for the bedside—away, that is, from the morality of decisions made by individual patients and their physicians—to take seriously the multiple and unequal worlds of health care within which choices are made about how we will live and how we will die, what we will invest in, what ends medical science will seek, and how new technologies will be used.

Increasingly, the lens through which we view medical decision making presupposes the interdependence not only of individuals within families or communities but also the interdependence of communities, regions, nations, and continents. As a consequence, caregivers have begun to appreciate to a new degree the way in which health care choices are embedded, emerging within and responding to ever larger and more complex "webs of life."

Moreover, as Christian ethicists have confronted the complexity and enormity of the AIDS pandemic, they have become more attentive to the multiple factors that account for vastly differing vulnerabilities to infection and death, including deeply entrenched patterns of wealth and poverty, long-term political and social instabilities, global economic systems that favor the interests of Western industrial nations, and the role of cultural and religious norms concerning sexuality and gender. More than anything else, AIDS has made obvious the limits of bioethical approaches that privilege individual autonomy while ignoring the questions of social justice raised by persistent and, in some cases, growing disparities in access to health care and other basic human goods. Today, Christian bioethics is pressed not so much to abandon its foundational commitment to promoting the dignity of each human person but, rather, to ask what that commitment entails in the context of a global common good. In other words, bioethics has become ever more self-consciously *social* ethics.[2]

One way to explore the significance of this shift is to consider the development of genetic technologies in light of the multiple and unequal worlds of health care that exist both here in the United States and around the world. Although progress from research to clinical application has been slow, few advances in science and medicine

hold more promise for alleviating human suffering and advancing understanding of health and disease than the Human Genome Project (HGP), the 13-year effort funded by the U.S. Department of Energy and the National Institutes of Health (NIH) to map and sequence the human genome.[3]

Since publication of the complete sequence in April 2003, the human genome has been called the "code of codes," the "book of life," and "science's holy grail." Still, even though much has been written on the HGP's social and ethical implications, there has been relatively little reflection on the potential for a "genomic divide" between what the Princeton molecular biologist Lee Silver, PhD, calls the "genrich" (those who will have access to genetic breakthroughs) and the "gennaturals" (those who will live with the natural lottery) in the United States and, in the larger world, between nations that are rich in genomic technology and those that are not.[4]

Bioethics literature is full of debates concerning genetic privacy and the dissemination and use of genetic information. Rarely, however, have the questions pressed upon Christian bioethics by what we Catholics call the "option for the poor" been considered in a serious and sustained way. Such questions include:

- How will advances in genomics improve health in developing countries, particularly those areas already ravished by AIDS?
- How are genetic investments likely to affect health care for the more than 45 million people in the United States who are currently uninsured or underinsured?
- What values will govern our decisions concerning who will reap the benefits of the genetic revolution and who will bear the burdens?

When emerging genetic technologies are viewed through the lens of the Roman Catholic social tradition, it becomes clear not only why these questions are important but also why they deserve to be at the center—rather than at the margins—of our ministry's analysis.[5]

Genomics and the "10/90 Gap"

The HGP is likely to revolutionize the way medicine is practiced because it will allow for the identification of genetically based vulnerabilities (perhaps even before birth) and the use of information about individual genetic variations in prescribing drugs and choosing doses, and because it will eventually allow the development of therapeutic interventions on the genetic level.[6]

On the face of it, it may be hard to imagine what relevance such developments might have for areas of the world whose annual health care expenditures are, for example, less than the cost in U.S. dollars of a single diagnostic test for inherited susceptibility to breast cancer. What relevance would a test that currently costs between $300 and $3,000 have for countries like the Democratic Republic of the Congo, which in 2002 spent $15 per capita on health care; Sierra Leone, which spent $27 per capita; or Rwanda, which spent $48 per capita?[7] It is undeniable that, in many regions, access to basic health care, clean water, adequate nutrition, maternal and child care, and the means to prevent and treat HIV/AIDS are far more pressing problems than whether affordable genetic testing for osteoporosis will become available.[8] Yet emerging international voices, including voices from developing countries, suggest that assuming the irrelevance of genomics for low-income areas is dangerous in at least two ways:

- It overlooks the relation between the values that govern investments in medicine and public health generally and the values that will govern investments in genomics
- It underestimates the potential contribution of genomics to global public health goals

Genomics and World Health, a 2002 report published by the World Health Organization (WHO), begins by acknowledging what is often called the "10/90 gap," the fact that "90% of health research dollars are spent on the health problems of 10% of the world's population."[9] According to WHO, several features of genomics research reflect and potentially exacerbate this gap:

> Most genomics research was initially undertaken in the public sector of developed countries. But a recent survey reports that private-company spending on genomics has overtaken and is now substantially higher than government and not-for-profit spending. The concentration of research funding in developed countries as well as in the private sector has implications for setting research priorities and for accessing the products of research. . . . The private sector does not invest in research aimed at diagnostics or therapeutics for diseases that are predominant in developing countries because the populations that are afflicted and most likely to need them do not have purchasing power. In order to ensure high returns on their investments, companies tend to focus their research and development efforts on products aimed at diseases and health problems that are most prevalent among the populations of the developed countries.[10]

The "genrich" are more likely than others to benefit from genomic science.

In 1997, WHO estimated that low- and medium-income countries accounted for only 20 percent of the global pharmaceutical market, even though they made up over 80 percent of the world's population.[11] In 2004, the United States continued to dominate the world pharmaceutical market, accounting for 35 percent of newly introduced products; Western European countries accounted for another 41 percent.[12] According to one industry forecaster, biotechnology drugs accounted in 2004 for 27 percent of those in the active research and development "pipeline" and for 10 percent of the global pharmaceutical market.

Even public research funding is driven in large part by market concerns through the increasingly common partnerships between government and private industry. As *Genomics and World Health* points out, "public research programs . . . tend to be focused on diseases such as cancer and cardiovascular diseases that are priorities in developed countries" whose economic interests drive global medical research agendas.[13] As WHO has said: "It has been estimated, for example, that pneumonia, diarrhea, tuberculosis and malaria, which together accounted for more than 20% of the disease burden of the world, receive less than 1% of the total public and private funds devoted to health research. . . . It was also estimated that in 1998, out of the US$70 billion global spending on health research, only US$300 million was directed to vaccines for HIV/AIDS and US$ 100 million to malarial research."[14]

The World Health Organization has noted that of the 1,233 new drugs marketed between 1975 and 1999, only 13 were approved specifically for tropical diseases.

A study by the Wellcome Trust in the United Kingdom estimated that malaria research in 1998 worldwide totaled $84 million. Since malaria killed between 1 and 2 million people that year, the total investment amounted to approximately $42 of research spending per malaria death.[15] Despite recent increases in international commitments to battle diseases that disproportionately affect the developing world, funding for diseases like malaria remains inadequate, said Jeffrey Sachs, director of the Earth Institute at Columbia University. Although lauding signs of progress, Sachs noted that, during its first round of funding in 2002, the UN Global Fund to Fight AIDS, TB, and Malaria committed only $22 million (out of a $616 million total) for malaria programs.[16]

Just as research priorities are heavily driven by the economic interests of nations in the world's industrial north, so also are the products of research. WHO noted that "of the 1,233 new drugs marketed between 1975 and 1999, only 13 were approved specifically for tropical diseases. Furthermore, of these, six were developed by WHO, United Nations Development Program (UNDP) and UNDP/World Bank/WHO-supported Special Program for Research and Training in Tropical Diseases."[17] Even a quick glance at the best-selling drugs in the world market for 2004 illustrates the predominance of "rich country" investments: Cholesterol-lowering drugs led the market, with sales of $30 billion (led by Lipitor, with sales totaling $12 billion), followed by anti-ulcerants, treatments for cardiovascular and central nervous system disorders, antidepressants, and antihypertensives.[18] Industry analysts look to cancer drugs for the next big boom; according to IMS Health, "oncology projects accounted for almost 30% of the total industry R&D pipeline as of February 2005." IMS Health predicts that the "cancer market will be worth more than $40 billion by 2008."

Inequality Begins at Home

Some experts fear that concentration of investments in genomics in high-income, developed regions will skew genomic research disproportionately toward the development of potentially lucrative products. These concerns are at least initially borne out by present patterns of research activity. According to the U.S. Department of Energy, there were in 2002 600 clinical gene-therapy trials involving 3,500 patients going on worldwide. The vast majority of these trials were located in the United States (81 percent), followed by Europe (16 percent). Most trials focus on various types of cancers.[19]

Some critics have charged that the "10/90 gap" is a red herring. They argue that—given rising rates of obesity and obesity-related health problems worldwide, as well as rising rates of cancer in developing countries—distinctions between "rich country" and "poor country" diseases are misleading. They say, moreover, that the disease burden in developing countries is more a function of poverty and poor public health infrastructure than a lack of research and development efforts aimed at the diseases that predominate there. Diseases such as tuberculosis, malaria, and schistosomiasis, these critics argue, are both preventable and treatable with existing methods.[20]

But such objections miss the point of highlighting the gap between investments in rich countries, on one hand, and poor-country priorities, on the other. When profitability exclusively

(or even overwhelmingly) drives research priorities, the products that are available are not only determined by market attractiveness but also are frequently priced beyond poor countries' means. Moreover, the prevailing market ethos presumes a producer/consumer posture toward genomics rather than an appreciation for genetic advances as public or "common" goods.

Such a posture results in multiple built-in disincentives to invest in public-health oriented or public-interest research. Following the publication of *Genomics and World Health,* 28 health research experts, either from developing countries or specialists in public health there, were asked to name the "top ten biotechnologies for improving health in the developing countries." At the top of their list were "modified molecular technologies for affordable, simple diagnosis of infectious diseases and recombinant technologies to develop vaccines against infectious diseases."[21] The respondents also mentioned technologies for more efficient drug and vaccine delivery systems and for environmental improvement, such as new approaches to sanitation and bioremediation.

However, existing market realities discourage investment in products such as the infectious disease vaccines that the developing world especially needs. Ruth Levine, of the Washington, DC-based Center for Global Development, has described some of the reasons why the development of such vaccines is unattractive to pharmaceutical companies. According to Levine, "vaccines make up less than two percent of the $340 billion global pharmaceutical market."[22] The "developing country vaccine market" is even smaller, "a mere $500 million or about one-tenth of a percent of annual global pharmaceutical sales." As a result, the number of big companies undertaking research on new vaccines has declined significantly over the past 20 years. Only three firms in the United States are licensed to produce childhood vaccines today (versus seven in the 1980s), and those three hesitate to invest in vaccines that would primarily be sold to customers in low-income countries.

Levine argues that limited research subsidies may work to hamper, rather than facilitate, development of solutions to medical problems that afflict the developing world. For example, a recent study by GlaxoSmithKline scientists, funded in part by the Bill and Melinda Gates Foundation, is showing some promise for the prevention of malaria. However, Levine notes, public and private donors must "pick a winner" early. As a result, other vaccine candidates, which in principle could prove to be even more effective, may never be developed.

Moreover, the introduction of new and highly sophisticated treatments risks simply exacerbating existing inequities. Audrey Chapman, PhD, a bioethicist with the American Association for the Advancement of Science, uses the case of inheritable genetic modifications—technologies allowing for the modification of a set of genes that can then be transmitted to one's offspring—as an illustration of the problem.[23] Although Chapman's topic is the introduction of genetic technologies into U.S. health care, the point she makes—about the relationship between factors conditioning access to highly sophisticated, high-cost treatment, on one hand, and factors *likely* to condition access to high-demand genetic technologies, on the other—is valid for thinking about access to genetic advances in general.

Market realities discourage investment in pharmaceutical products that the developing world especially needs.

In asking whom technologies are this sort are likely to benefit, Chapman suggests that the answer will be found by taking into account the interplay of four factors: long-standing patterns of inequalities of access to health care; a nonexistent system of universal health care; a projected scarcity of the availability of genetic services relative to demand; and the likely high cost of such interventions.[24]

Chapman notes the obvious facts about the current U.S. health care system:

> Problems in obtaining access to health care are unfairly distributed throughout our society. Blacks, Hispanics, and other minorities tend to receive lower quality health care than whites do . . . as a result of lower incomes, inadequate insurance coverage, and the absence of doctors in their areas of residence. Minorities are far more likely to be uninsured as compared to whites: Minorities comprised 46 percent of the uninsured in 2000, although these groups represented only 24 percent of the United States population. In 2001, 37.7 percent of the uninsured were Hispanic and 20.2 percent African American, compared to 14 percent who were white.[25]

Furthermore, various studies have documented a significant "therapeutic discrimination" in the type and quality of health care that U.S. minorities receive. A 1999 Institute of Medicine (IOM) report concluded that "racial and ethnic minori-

ties in the United States receive notably lower-quality health care, even when they have the same incomes, insurance coverage, and medical conditions as whites."[26] The differences were especially significant for high-technology interventions, such as organ transplants and open heart surgery. An earlier IOM study (*The Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved*) had raised similar concerns about inequities in research priorities. It concluded that NIH funding for research targeting minority and medically underserved populations was both inadequate and unequal in comparison to research targeting nonminority populations.[27]

Considering these findings, it seems safe to assume that "current limitations on access to health care, particularly high technology interventions, will also likely operate with respect to genetic services."[28] High-demand genetic therapies, as well as enhancement interventions, are likely to be both very costly and (like in vitro fertilization and other reproductive technologies) available only to those who are willing and able to pay for them. Even if universal health coverage were to be adopted in the United States, underwriting access to some forms of genetic services (e.g., gene therapy for muscular dystrophy), current practice suggests that "the very groups who currently lack access to medical care, the poor and ethnic and racial minorities, are likely to still be disadvantaged."[29]

High-demand genetic therapies are likely to be very costly, available only to those willing and able to pay for them.

Unless our nation addresses underlying factors in disparities in access—such as the fact that both health care facilities and professionals tend to be located more often in areas where nonminority people live than in those where minority people do—claims made about the promises of genetics for advancing health for all are apt to be false, or at least only partially true.[30]

The factors accounting for disparities between high- and low-income nations in medical resources and research benefits differ from those accounting for disparities between high- and low-income groups in the United States. Still, they suggest that disparities in access to emerging genetic technologies are likely to have similar causes. Products have been developed and marketed to treat diseases, such as cancer and hypertension, long characteristic of developed nations. Today those illnesses are beginning to turn up in developing countries. Will those countries have access to new antihypertensive and anticancer products? Not if the conditions that made access to high-cost, high-demand therapies for HIV/AIDS virtually impossible in so many areas continue to prevail.

Genomics, Health, and the Common Good

Those who argue for equitable access to the benefits of genomic research make two crucial assumptions: first, that therapeutic advances in genetics are the fruit of a common human heritage; second, that access to health care is necessary for the protection of human dignity and the promotion of the common good. One can argue that the HGP is a "global public good" without referring to any particular religious tradition; and arguments defending equitable access to health care do not depend on religious convictions. Yet there is in Catholic social thought a rich tradition concerning the meanings of both *health* and *the common good* that provides an invaluable resource for reflecting on the challenges described above.

The Second Vatican Council defined the common good as "the sum of those conditions of social life which allow social groups and their members relatively thorough and ready access to their own fulfillment."[31] The common good is the "comprehensive human good of all who make up society," encompassing all the spiritual and material aspects that make possible a full and dignified human life. The common good concerns, in the words of the Catholic philosopher Jacques Maritain, the "common good of *human persons* . . . their communion in good living."[32] It is realized when prevailing social institutions function interdependently for the promotion of, among other things, "strong family life, strong educational institutions, rich cultural and artistic activity," and the "provision of material goods sufficient to meet the needs of all members of society and to allow participation in the civic community."[33]

Although St. Thomas Aquinas did not himself develop a full theory of the common good, the roots of this understanding of the relationship between civic participation and human flourishing come from his account of the natural orientation of the self toward community. As Susanne M. DeCrane has noted, "for Aquinas, morality emerges from and in a communal context. The inherent sociality of the human person results in some form of society or community being the context in which the person has the best hope of growing in her goodness and happiness. Human society exists (not as an end itself but) in order to

facilitate and promote the common good of the group because in so doing the circumstances and necessities of full human life can be provided for all members."[34]

From this understanding of the human person as essentially communal, Catholic social thought advances a conception of justice as *relational* and *mutual*.[35] What is required of individuals, institutions, and the social order is specified by the concrete needs of individual persons as they seek to achieve fully human membership in various communities. For this reason, "basic justice demands the establishment of minimum levels of participation in the life of the human community for all persons."[36] As DeCrane puts it, "society is ordered toward an equity in the distribution of the goods of the group if it is to fulfill its reason for existence."[37] It is in this context that the right to adequate health care—as well as claims to a fair share of the benefits of genomics research—is to be understood. Adequate health care and protection from the threat of disease are human rights precisely because they are necessary for the full realization of human potential and for the fulfillment of social responsibilities.

When social institutions or policies fail to guarantee equitable access to the means for a dignified human life, justice will demand preferential treatment for those whose basic needs are not being met. Indeed, for Catholic social thought, the state of the least well-off stands as a challenge to and an indictment of all proposals for social organization. A preferential option for the poor entails a responsibility to examine social, economic, political, and cultural institutions and practices in light of the general requirements of human flourishing and to evaluate social policy from the perspective of those who are variously marginalized within the present order. What is at stake in "opting for the poor" is not simply trying to "change who is on top" but attending to the constellation of factors—poverty, geography, race, or gender—that systematically undermine full participation. The goal is to include those who have been marginalized in an order oriented toward human development in common.

If concerns about a growing "genomics divide" (domestically as well as globally) are at all well-founded, they join more general concerns—about growing gaps between rich and poor, between prosperous nations of the industrial northern hemisphere and sustenance-level nations of the south—that can be found in much Catholic social teaching, especially in contemporary social encyclicals such as *Solicitudo Rei Socialis* and *Centesimus Annus*. It was in light of such growing divides that the U.S. Catholic bishops argued in their 1986 pastoral letter on the economy that "the obligation to provide justice for all means that the poor have the single most urgent economic claim on the conscience of the nation."[38]

But what exactly does it mean to provide "justice for all" in the context of genetic research and technology? What might "justice as participation" imply for how we value medical interventions or how we distribute medical goods, particularly as we are increasingly aware of a common good that is global in scope?

What exactly does it mean to provide "justice for all" in the context of genetic research and technology?

In *Harnessing the Promise of Genomics*, the Catholic Health Association has identified four key principles for reflecting on the obligations of justice with respect to genomic advances: respect for human dignity, relationality, solidarity, and subsidiarity.[39] These principles are not incompatible with the familiar principles of medical ethics. Respect for human dignity—for the fundamental equality of all human persons as *imago dei* (as representing the image and likeness of God)—presupposes that we respect every competent person's right to make health care choices in light of his or her own needs and values; it presupposes the right, when one is in the care of a trusted provider, to be neither harmed, exploited, manipulated, nor discriminated against on the basis of genetic or any other disease or disability; and it presupposes respect for privacy in the use of genetic information.

However, as we have seen, for the Catholic tradition, respect for persons as such is always expressed within a given set of communal relations. Thus, as one writer puts it, "justice requires that we see ourselves as bound in a covenant of life with life, in which human freedom and choice is always coupled with a sense of social responsibility."[40] The principle of *relationality* brings individual rights and duties into the conversation about the common good, asking how choices create conditions for the flourishing of all members of society. In the context of genetic technologies, a concern for relationality raises questions about our responsibilities to future generations; about how we set priorities for genetic research; about how we weigh the advantages to be gained through genetic technologies against other means for addressing disease, disability, and death; and about how we will distribute genetic services in light of the multiplicity of needs and limitations in resources.

Justice and Genetics: Whose Holy Grail?

The importance of ensuring the capacity for humane participation in society for all members calls for active *solidarity*. As noted, the "option for the poor," is not an adversarial slogan that pits one group or class against another. Rather, it expresses the recognition that the extent of suffering by some is a measure of how far we are from being a true community of persons."[41]

Solidarity captures the sense in which the claims of justice exerted by the poor enjoin not only our emotions but also our thinking about how we produce and use goods, as well as how we will organize our society. These are claims not simply to charity (sharing a surplus) but to justice—a rightful share of what is owed to all. Justice will require a reorientation of the use of goods as well as of the way society is organized to meet needs in light of the claims of the poor. Thus, in the context of genomics, the enduring commitment of Catholic health care "to the disadvantaged and our option for the poor requires a careful and delicate balancing—for example, balancing the pursuit of the goods of genomics with efforts to ensure that the basic human needs of all our citizens (and those most in need around the world) are adequately met; balancing the pursuit of genomics with meeting the health needs of the poor and effecting reform of an unjust health care system; and ensuring that the benefits of genomics are as available to the disadvantaged as they are to all other citizens."[42]

As in other areas, globalization presses us to think in new ways about cooperation and governance.

The principle of *subsidiarity* recognizes that the common good is best promoted and protected by enhancing the contribution and cooperation of various groups—in other words, by enabling various actors on different levels to act collaboratively. As in other areas, globalization presses us to imagine new ways of thinking about cooperation and governance as borders become more fluid and as we become more aware of the need for cooperative networks on a global scale. Subsidiarity pushes bioethics in two directions—toward the promotion of transnational participatory collaboration for equity, on one hand, and toward the further development of local capacity, on the other. These concerns encompass not only how partnerships might be forged between regions that are sophisticated about genomic technology and less sophisticated ones, but also how developments in biotechnology will interface with local and regional problems in health care delivery and infrastructure. *Genomics and World Health* makes the obvious but important point that "any benefits that result from genomics research will be irrelevant to countries that do not have a functioning health care system in place."[43]

Although one could say much more about the implications these principles have for decisions concerning access to genetic technologies (given existing global realities), the direction such an analysis would take should now be clear. As with efforts to bring affordable drugs to AIDS-ridden regions, strategies for mobilizing international cooperation for equitable access to biotechnologies must include assistance for developing nations in addressing such basic care delivery issues as training, education, and community organization. Needed also is support for the development of local capacity in bioethics, so that decisions about the conduct of research and the clinical application of developments in biotechnology incorporate and respect the religious and cultural values of those involved or affected. Some recognition on the part of the United States of the importance of this kind of empowerment can be seen in the NIH-funded "Communities of Color and Genetics Policy" program, which seeks to engage minorities in policy development to address issues of particular relevance for African-American and Latino communities.[44]

Discussing both the promises and the perils of global interdependence, Cahill argues that "a 'civic understanding of health,' not merely a consumerist one, [must emerge] at the global level if information and communication technologies are to be used not only to serve the market, but to envision and realize shared goods of health care in a newly integrated world."[45] One feature of such an understanding of health is a critique of what is often called "the culture of ownership" that dominates the research and regulation environment in biotechnology. Many people around the world have been sharply critical of current intellectual property laws that allow patenting of genetic material and control the rules under which drugs are produced and marketed. Such laws disregard the nature of genes (as naturally recurring information) and create monopolies on genetic information that are counter to the public interest.[46]

The most compelling arguments in this vein have significant overlap with Catholic social teaching on the universal destination of goods. Critics of the rush to patenting (and the overall inequities involved in access to the benefits of genomic research) argue that the character of the HGP, as a multinational cooperative effort aimed at identifying a common genetic code, makes its

discoveries inherently "global public goods." Cahill and others have called for the creation of an "international or transnational forum for creating and implementing global policy" on the dissemination and use of genetic information, a forum that would be inclusive and participatory.[47] Some promising proposals are being offered as well for breaking the impasse between the claims of pharmaceutical corporations to protection against engaging in financially unsound research, on one hand, and the needs of developing countries for innovative approaches to the prevention and treatment of disease, on the other. Approaches such as patent regulations that encourage differential pricing for products developed for public health interests and government-guaranteed price packages for the development of vaccines aimed at underserved populations could encourage more companies to take the necessary risks.

A global option for the poor also encourages research collaboration between genetically advanced or more advanced countries (not all of which are developed nations) and genetically less advanced. According to Tikki Pang, PhD, WHO's director of Research Policy and Cooperation, asking ourselves how biotechnologies might serve public health in the developing world is a positive step, but doing so "must be accompanied by a genuine willingness on the part of developed countries and the pharmaceutical and biotechnology industries to share knowledge and help poorer countries apply such knowledge to solving their health problems."[48] Pang argues further that the "developed world must be prepared to invest more money in research in developing countries . . . in a spirit of helping developing countries ultimately to help themselves." Symbolizing its hopes, WHO released its report on genomics at a conference, hosted by the Africa Human Genome Initiative, that drew "world renowned super-scientists" along with leading African and South African scholars.[49] Pang and others endorsed the development of a Global Health Research Fund that would make resources for research available through peer-reviewed application to every country.[50]

It perhaps goes without saying that the big question concerning equity of access to genetic advances is: What can be done on behalf of the poor and the marginalized in the face of powerful counter values—profitability, self-interest, and market share—and in the face of such powerful actors as multinational corporations? How is interdependence to be transformed into solidarity? Although arguments for transnational or global governance structures appear compelling, there is no consensus about what such structures would look like or how exactly they would gain their authority.

Some experts—drawing on the interconnection of human rights, global public health, and biotechnology—argue for the formation of an international supervisory agency (perhaps as part of the United Nations Educational, Scientific, and Cultural Organization, UNESCO) to oversee research and development in genomics. Such an agency would possess regulatory power derived from documents such as UNESCO's *Universal Declaration on the Human Genome and Human Rights.*[51] The Catholic health ministry could take up the option for the poor by joining efforts to develop a workable vehicle for transnational solidarity around public health initiatives and working for its implementation.

However, Cahill has persuasively argued that the most important work religious groups can do on behalf of the poor may lie, not in the field of law and regulation, but rather in cooperation through global advocacy networks. Religion can and should be a powerful force for education, for joining parties in opposition to inequities and violations of human rights, and for consolidating an alternate vision in the face of the all-encompassing power of the market.[52]

As an example of the potential, Cahill points to international grassroots organizing in opposition to the imposition of genetically modified foods on developing countries, with its accompanying inattention to such foods' potential for displacing local crops. The effort she describes, involving religious groups, nongovernmental organizations, and episcopal conferences, has caught the attention of policy makers. Similar grassroots actions, involving both religious groups and secular advocacy groups, publicized the failure of U.S. and European pharmaceutical companies to make affordable drugs available for countries devastated by AIDS, especially in sub-Saharan Africa—and this publicity ultimately led to positive changes in pricing policies and to U.S. economic commitments to address AIDS.

The most recent report of the Global Forum for Health Research notes that "remarkable progress has been made in recent years in the development of international collaboration to solve major global health problems: between 1995 and 2003, more than 70 public-private

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partnerships and networks were created to address diseases such as HIV/AIDS, TB, malaria, and leishmaniasis. The challenge for the future will be to ensure their continued viability."[53]

A Bioethics of the Common Good

Christian ethics is inescapably an ethics of the common good.

Christian bioethics is today inescapably bound up with social ethics; it is inescapably a bioethics of the common good. The risks of ignoring the social and global dimensions of health care choices, of overlooking the multiple worlds of health care that exist in this nation and around the world, are dramatically illustrated in the HGP and the genetic revolution now under way.

Genomics promise to open new frontiers in the pursuit of health. But they also threaten to widen old gaps between developed and developing countries. There are many images used to describe the achievement of the HGP and its implications for our shared future. The philosopher Albert Jonsen has likened the genomics age to the beginning of the colonial period. He writes: "The ships that sailed from Europe five centuries ago not only mapped the world—they inaugurated social, political and economic events that radically changed humankind's view of itself and nations' views of their destinies. The rapidly redrawn map of discovery and colonization depicted areas of glorious achievement and areas of deplorable tragedy."[54]

The HGP represents a new kind of mapping. Whether it is used to chart areas of achievement or areas of continued tragedy will depend on choices made, for the most part, by those of us who live in the "90%" world. Will we choose profit, utility, and individual liberty—or respect for human dignity, solidarity, and concern for the common good? ■

NOTES

1. Lisa Sowle Cahill, *Bioethics and the Common Good,* Marquette University Press, Milwaukee, 2004, pp. 8-9.
2. Cahill, p. 8.
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