

GENETICS AND ETHICS

Issues *and* Implications of the Human Genome Project

IN JUNE 2000, the public and private heads of the Human Genome Project announced the virtual completion of the sequencing of the human genome. This extraordinary accomplishment occurred several years earlier than what originally had been thought possible. Eight months later, in mid-February 2001, the same two scientists announced the results of the first analysis of the rough draft of the human genetic code. Among the reported discoveries: Fewer human genes exist than previously believed; humans share nearly all their genes with mice and worms and even some bacteria; and, genetically, humans of all races are

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almost identical to one another. These discoveries and others associated with the analysis changed the understanding of the human genome in fundamental ways. The knowledge gained could have a profound impact on the treatment of complex human diseases within the next five years.

This report was not the only major genetics-related news to be released in the first six weeks of 2001. Two scientists, an American and an Italian, announced that they intend to collaborate to clone the first human being. The British government declared that it will permit the creation of human embryos (through in vitro fertilization) for the purpose of obtaining stem cells. Several other groups of scientists have also reported attempting to use "somatic nuclear transfer" (cloning) to obtain stem cells. All in the first six weeks of the year! Many other genetic milestones have most likely been reached but not yet made public.

The pace of advancement in human genetics is staggering. These developments wouldn't be quite so disturbing if they had few implications that would touch peoples' lives or if the implications were still far off. But neither is the case. The implications are profound—for our self-understanding as human beings, for the diagnosis and treatment of disease, and for the organization, delivery, and financing of health care. Many implications of genetic advances are already being experienced. Others are imminent.

One of the most pressing questions facing the human community, and specifically the health care community, is whether we will allow ourselves to be led by developments in genetics or attempt to guide how the knowledge gained is used in the service of humankind. If we opt for the latter, a profound urgency exists—in education, ethical and theological reflection, public policy, and health care delivery.

This special section of *Health Progress* is both a clarion call as well as a very modest attempt to survey the promises and challenges of advancements in human genetics and to provide some ethical, legal, and theological considerations for beginning to deal with them. Given the vast scope of genetics, the emphasis has been on some of those developments that already have or soon will have a significant impact on Catholic health care facilities and systems as well as on the ministry as a whole.

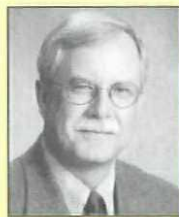
Philip Reilly, on p. 24, identifies major challenges we will be grappling with during the next 10, 15, and 20 years. Kevin O'Rourke, OP (p. 28), raises concerns about the adequacy of genetic counseling for the increasing numbers of individuals who will be undergoing testing in the

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years ahead, as well as about the moral permissibility of using cultured stem cells originally derived from aborted fetuses or spare embryos in Catholic research facilities. On p. 33, Thomas Shannon explores the issue of amniocentesis for Catholic health care; this procedure will be even more challenging in the future as it becomes possible to detect increasing numbers of genetic anomalies prenatally. Carol Tauer addresses some of the most difficult issues associated with genetic testing—rights and responsibilities with regard to disclosure of personal genetic information (p. 36) as well as protection of the privacy of genetic information and prevention of genetic discrimination (p. 48). The legal and ethical dimensions of genetic privacy are also considered by Cathleen Kaveny on p. 43, along with some of the legal and ethical aspects of cloning.

Several contributors to this issue offer theological considerations from the Catholic Christian tradition that provide elements of a roadmap to better navigate the territory of genetic advances. In his column on p. 6, Rev. Michael D. Place, STD, identifies what might be considered directional signs or indicators drawn from foundational Christian beliefs. Therese Lysaught (p. 54) examines the "soft underbelly" of genetic testing and three theological themes that can provide a counterbalance: healing, the dignity of the human person, and eschatology. Finally, Card. Francis George, OMI (p. 60), sketches a Christian vision for bioethics generally, and genetics in particular, that is grounded in a Christian anthropology, in particular a profound respect for human dignity.

These pages hold few answers. If anything, these articles will make our lives and work more complex by what they bring to the fore and by the questions they raise. They are meant to contribute to the initiation of conversation, to study, and to debate. Much work lies ahead. Whether and how we undertake this work will determine if we are successful in, as Philip Reilly states, "harnessing these powerful tools for the public good to serve ethical goals." This, as he says, is *our* challenge. □



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