

# The Challenge of Genetics

BY REV. MICHAEL D. PLACE, STD

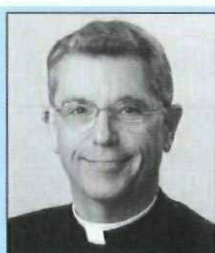
**D**uring the fall of 2000, we had the wonderful opportunity to begin the process of planning association activities for fiscal year 2002. The first stage of those efforts involved a joint meeting of many of our administrative committees (which provide advice and counsel to staff) as well as three member strategy sessions held in Baltimore, Chicago, and San Francisco. An important component of all these meetings was the topic addressed in the special section of this issue of *Health Progress*: the genetic revolution.

A short video of a presentation by Philip Reilly, MD, PhD, given at the 85th Catholic Health Assembly in June 2000 introduced each of the discussions. (See p. 24 for an adaptation of Dr. Reilly's presentation, "The Human Genome Project: Recent Genetic Advances Will Have Far-Reaching Implications for Catholic Health Care.") In all the meetings, the ensuing conversation about the implications of scientific advancement in the field of genetics was extremely engaged and thoughtful. The accompanying **Box** (see p. 8) highlights several of the themes, challenges, and possible responses that surfaced in these discussions.

Substantial consensus existed regarding the most appropriate responses and key areas to focus on in this ever-changing arena. In summary, participants suggested that the Catholic Health Association, as the *ministry gathered*, focus on:

- Promoting education on genetic advancements for everyone involved in the ministry, as well as for the public
- Engaging in broad-based collaboration with partners (physicians, scientists, research institutions) and other "like-minded" organizations
- Advocating the protection of individual rights and the common good within a developed ethical framework
- Serving as a catalyst in initiating the necessary debate and discussion

A theme that emerged in our many conversations was the need for our contribution to the dialogue on genetic advancements to be as positive as possible. A real concern arose that, as a church and as a ministry



*Fr. Place is  
president and chief  
executive officer,  
Catholic Health  
Association,  
St. Louis.*

of the church, we not be perceived as a "naysayer" that only points out the evils associated with genetic discovery. Participants saw this as an opportunity for the church to act in a way quite different from the image of how it responded to Galileo and the birth of modern science. Although I personally share this concern, I also believe, because of the richness of our theological heritage, that we are uniquely positioned to play a significant role in a national dialogue about how we will address the incredible opportunities associated with the genetic revolution.

Over the course of the coming months, CHA staff and board members will engage in this valuable reflection and will chart our future direction. We will share those decisions with the ministry when we announce next year's association projects and initiatives.

## CATHOLIC HERITAGE AND THE GENETIC REVOLUTION

When debating the challenges of the genetic revolution, we must address the issues from within the solid framework of our theological heritage. When our Catholic heritage looks at creation, it sees the power and the glory of a loving God. As the Genesis account tells us, God looked at what had been created and saw that it was good. Consequently, a truly Catholic perspective is one that is optimistic about creation and its potentiality. Similarly, we believe that, as human beings, we are made in the image and likeness of God. Because we are also configured in a special way to the second person, the Word (who is the source of all knowledge), we consider the search for the truth of knowledge to be a holy venture. In fact, the Second Vatican Council spoke about the distinctive vocation of the human sciences and of a certain type of autonomy that should be accorded to them. We also take seriously the Genesis image of God the Creator giving to Adam and Eve the responsibility to steward the great gift of creation. The advancement of creation, the elimination of illness, and the curing of disease are distinctive aspects of the human vocation.

To these themes, which are strikingly congru-



ent with much of the mindset of contemporary science, we add others. First, while recognizing the giftedness that is creation, we also affirm that this giftedness is not the product of a random or accidental evolution, but that creation is associated with a purpose that transcends human creativity or knowledge. We live, then, with a creative tension between the expansive potential of human learning and the fact that such learning is accountable to higher calling: fidelity to the meaning or purpose that creation received from its Creator. Hence, a certain humility is always associated with the pursuit of human knowledge.

That humility is grounded not just in our honoring the hand of God, but also in accepting the reality of human sinfulness. Although redeemed by the blood of the cross and the power of the Resurrection, we know that humanity still bears the marks of human sinfulness. At times we can—and do—bring injury to ourselves, to others, and to the human family. The reality of sinfulness requires that we always engage in a process of discernment to ensure that our efforts are not misdirected.

Our theological heritage also reminds us that the human journey is not a solitary one; we are social beings who are responsible for preserving and promoting the solidarity of the human family. We do this, in part, by promoting within the family of faith an authentic understanding of a consistent ethic of life that is grounded in an activist attentiveness to those who are the weakest and most vulnerable. This ethic is why we are present in the world as both agents of transformation and prophetic witnesses. Our consistent ethic allows us to carry on a dialogue in a reasoned way about issues critical to the future of the human family with a persuasive cohesiveness of perspective. When that dialogue fails, however, it also requires that we proclaim what is true even if the truth is unpopular.

What does this perspective say regarding the genetic revolution? I believe an authentic Catholic response is one of enthusiasm. We are at the dawn of a new and exciting moment in the history of the human family. One thinks of equivalent watershed events: the discovery of fire, the creation of iron tools, the invention of the printing press, the harnessing of electricity, and the breaking of the atom. Each of these events profoundly altered the course of human history. So, too, will the genetic era.

Catholic centers of higher education and our health care delivery centers of excellence must be active participants in both exploring and applying what is learned about human genetics. In fact, one can argue that we have a moral responsibility to

our patients to ensure that fruits of this research be allowed to transform our delivery practices—even if the research results require a profound realignment of how we serve a community.

We also have another responsibility: to speak of the accountability of scientific research and to require medical practice to be congruent with an authentic vision of the human person fully and adequately considered. How we witness to this vision while honoring the distinctive autonomy of human learning has not been and will not be easy. It requires clarity of purpose on the part of the ministry as well as an openness to dialogue with science. In the end, because the Word is the source of both the revealed truth and authentic human knowledge, a fundamental complementarity must exist between faith and science. For this to happen, the ministry must acknowledge the legitimate competency of science, and science must acknowledge that what is scientifically possible might not be in the best interests of humanity.

For example: Who owns the knowledge associated with the mapping of the human genome? Someone taking the free market approach would argue that the researcher owns it. Another perspective would argue that this knowledge is so fundamental to human well-being that it cannot be understood in the same proprietary way as the results of other scientific research. The value of human solidarity is proposed as being so significant that it tempers or nuances a customary understanding of intellectual property. An even more critical question—the answer to which could well determine the future of the human species—is whether we can *alter*, as distinguished from *repair*, our basic genetic infrastructure. In theory, one could argue that no *a priori* reason exists as to why this could not be done if it would truly advance the human condition. On the other hand, because we are dealing with consequences far beyond any human imagining, a sense of solidarity with our sisters and brothers who will be born in the next millennium makes us understandably hesitant to alter the existing patterns of evolution that have protected the long-term well-being of the human species.

Unfortunately, because of our history of witnessing to the social nature of human knowledge and our responsibility to do no harm to the generations that will follow, we can be perceived, or typecast, as the direct genetic descendants of those who sought to contain the work of Copernicus or silence Galileo.

How can we avoid this image and still fulfill our Christian responsibility as witnesses to, and





servants of, a higher truth? First, we must be at the table. We need to encourage and participate in the process of scientific research. Science is not an enemy, but a human gift. Second, we must learn the art of principled dialogue. Just as we honor the legitimacy of human knowledge, so too we do not abandon our beliefs and principles. Because we believe in the ultimate compatibility of revelation and human learning, we are motivated to stay in the dialogue for the long haul. Third, we pray for what could seem to be a contradictory gift: patient prophecy. On the one

hand, we can never equivocate when fundamental truth is at stake. On the other hand, we make sure fundamental truth is at issue before we fulfill this radical Christian responsibility. We also speak in a way that our truth can be heard even if it is rejected.

The path in front of us is clearly exciting and challenging. I am hopeful that as the ministry gathered we will be known as a significant contributor to successful utilization of the resources made available to the human family by the genetic revolution. □

## FINDINGS FROM THE 2000 MEMBER STRATEGY SESSIONS ON GENETICS

Themes	Challenges	Possible Responses
Education and communication	<ul style="list-style-type: none"> <li>• Lack of knowledge on the topic</li> <li>• Need for understanding between sponsors and bishops regarding theological and ethical consideration</li> <li>• Lack of organized dialogue between ministry and magisterium</li> <li>• Narrow base of consultation</li> <li>• Need for understanding of the boundaries of Catholic teaching</li> </ul>	<ul style="list-style-type: none"> <li>• Educate bishops, clergy, executives, clinicians, and patients</li> <li>• Engage bishops early in dialogue</li> <li>• Develop white papers</li> <li>• Initiate discussion with U.S. Conference of Catholic Bishops</li> <li>• Tap a wider scope of consultants (Catholic scientists and physicians)</li> <li>• Develop positions before issues arise</li> <li>• Lead the debate and keep it active</li> </ul>
Public policy	<ul style="list-style-type: none"> <li>• Past marginalization of Catholic health care in policy discussions</li> <li>• Rapid speed of scientific advancement</li> </ul>	<ul style="list-style-type: none"> <li>• Continue to fight for place "at the table"</li> <li>• Be first to set the agenda and standards</li> <li>• Develop theology and ethical code in a positive manner</li> </ul>
Access	<ul style="list-style-type: none"> <li>• Barriers to new treatments for those who lack money or education</li> <li>• Continuation of two-tiered system: one for the "haves" and one for the "have nots"</li> </ul>	<ul style="list-style-type: none"> <li>• Emphasize common good</li> <li>• Make value-based ethical decisions</li> <li>• Educate the public to raise issues</li> <li>• Continue to be a voice for the poor</li> </ul>
Genetic information	<ul style="list-style-type: none"> <li>• Potential for exploitation of genetic information</li> <li>• Employer decisions regarding genetic testing and insurance</li> <li>• Right to share genetic information</li> </ul>	<ul style="list-style-type: none"> <li>• Define parameters of acceptable practice</li> <li>• Lead the way by using the information appropriately as employers</li> <li>• Fund advances in genetic counseling</li> <li>• Develop an "expert bank" across systems</li> <li>• Support pastoral counseling around major issues: suffering, death, common good</li> <li>• Partner with Catholic universities where research is being done</li> <li>• Sponsor research or suggest Catholic foundations do so</li> </ul>

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