



# GENOMICS AND THE MINISTRY: THE EXECUTIVE PERSPECTIVE

*Four Leaders of Catholic Health Care Organizations  
Offer Their Opinions*

BY SCOTT  
McCONAHA



Mr. McConaha is a communications specialist, Catholic Health Association, St. Louis.

For the past year, *Health Progress* has been running a series of articles on genomic medicine and the ethical implications of genomic advances for the Catholic health ministry. Scientists and physicians have spelled out some of the facts regarding genomic advances in the areas of cardiology, neurology, oncology, and perinatal medicine/pediatrics. Accompanying each clinical-area article was commentary by a Catholic health care ethicist. Each ethics piece addressed some of the moral and ethical considerations/ramifications inherent in many current (and some hoped-for)

genomic practices.

As a way of wrapping up the genomics series, we have asked several ministry leaders to look back over the series and offer their views on genomic medicine's overarching implications for Catholic health care. Specifically, the leaders were asked to reflect on and answer two questions:

- From where you sit, what do you see as the implications of genomics for Catholic health care?
- In light of what has been said in the series of articles, how does Catholic health care need to be responding?

Here is what they said.

---

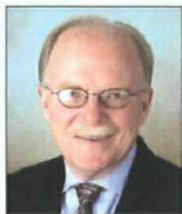
## MICHAEL D. CONNELLY

President/CEO  
Catholic Healthcare Partners, Cincinnati

The recent series of articles in *Health Progress* on genetics was both masterful and timely.

The series brought clarity to some of the mystery surrounding genetics for the health ministry. For example, it gave us a sense of timing surrounding genetic advances. In the short term, advances will be more limited to diagnostic care, whereas the longer term offers the potential for significant advances in therapeutic care.

The articles also highlighted for us the impact of genetic advances in such critical clinical areas as oncology, cardiology, neurology, and obstetrics.



Connelly

However, for us in Catholic health care, the fundamental issue associated with genomic medicine is its impact on our mission. The real challenge will be to utilize these genetic advances in science and medicine to strengthen our mission. The danger is that genetic science and technology could threaten our mission, rather than be a resource that advances the ministry. Advances in genetic medicine can be either an opportunity to promote, or a threat to diminish, our values and ethics as a critical dimension of health care.

As for the new science's implications, let me mention several here.

■ *Managing New Knowledge and Choice* The first implication of these advances is that they will test our ability to absorb significant amounts of new clinical knowledge and care choices. Today we are having difficulty learning and implementing advances in medical practice—this barrage of new medical advances will compound that prob-

lem. The field of genetics generates new diagnostics, new specialties, and new treatment options that require both patient and caregivers to become much more knowledgeable. The magnitude of this choice and information may become overwhelming for society.

■ *Managing Increased Expectations* In her article, Jessica Blasko asks: "Who will be responsible for meeting all of society's genomic 'wants and needs'? Genomic medicine will require physicians to become savvy at understanding, interpreting, and relaying genetic testing information. Physicians will be confronted with understanding patients' genomic makeups and their responsiveness to drugs in mainstream medicine" ("Genomics and Neurology: A Medical View," *Health Progress*, January-February 2006, p. 67). These genetic advances will elevate the consumer's already high expectations of health care and may diminish our resources to care for the growing number of uninsured in society.

■ *Managing Increased Ambiguity* Many genetic diseases are multifactorial (i.e., resulting from a combination of genetic, environmental, and behavioral factors). Whether the relevant genetic information concerns a cardiac condition or a neurological condition, it cannot be interpreted without taking into account lifestyle, environment, and other factors.

This multifactorial nature of genetics makes it difficult to ascertain the real implications of the new information. Newborn genetic screening in the United States currently illustrates this point. The number of genetic conditions for which screening is now performed ranges from a low of three mandated screens in some states to a high of 36 in others; each state determines what genetic screening is required. The debate around the different standards relates to the fact that no one knows whether helpful treatments exist, given the screening results. In fact, the screen outcomes can't even predict whether the child involved will ever show signs of serious disease. Yet we seem to want to know this genetic information. As the options for genetic screening and treatment increase, the ambiguity around the value of this information will also increase.

■ *Potential Increased Tension between Clinical Standards of Care and Catholic Standards of Care* Informed consent requires that clinicians inform their patients of relevant options for diagnosis and treatment. The article by Judith Pratt Rossiter, MD, ("Obstetrics and

Pediatrics: A Medical View," *Health Progress*, July-August 2005, pp. 9-13) illustrates the fact that a tension already exists between obstetricians and their patients concerning chromosome screening options.

As testing and treatment options expand, a gulf could grow between clinical standards and Catholic standards. This gulf has to do with the different values an individual or society might place on genetic information and therapy. Some could argue that the genetic information could only be used negatively, whereas others could say that genetic information may be fundamental to an informed choice. Carol A. Tauer, PhD, (in "Obstetrics and Pediatrics: An Ethical View," *Health Progress*, July-August 2005, pp. 13-18) discusses an interesting illustration of this tension when she raises the idea of premarital genetic screening. Does one need to know the genetic makeup of his or her proposed partner before making an informed choice about marriage? How much scientific information do we need to know about a prospective child or a prospective spouse to make an "informed choice"?

■ *Increased Misuse of Genetic Information* Given the market-driven nature of the U.S. economy, the potential misuse of genetic information to harm individuals is significant. Genetic profiles of individuals could be used by health insurers to deny coverage or by employers to deny employment. If employers begin relying on predictive genetic information, their doing so could create a whole category of individuals who are unemployable and uninsurable.

In this new world of genetics, values and ethics will be an increasingly important component of health care. Supporting, educating, and counseling people to understand their choices may be the ministry's greatest opportunity. This will require the Catholic health ministry to proactively develop its knowledge of genetics and define appropriate new services. We will also need to promote dialogue in our own church community and with others around the areas of tension and disagreement.

Finally, we can, as employers and citizens,

In this new world of genetics, values and ethics will be an increasingly important part of health care.

work proactively to protect privacy rights of individuals. This new world of genetics will call on the Catholic health ministry to more clearly define its role in the ethics and values of health care for our society.

**PETER MADDOX**

Senior Vice President,  
Business/Strategy/Corporate Development  
CHRISTUS Health, Irving, TX

The revolution in genetic science—which is gaining speed, momentum, and attention, and which comes bearing great promise—will expand human control over our bodies, food, and social structures. These advances will transform diagnosis, prevention, and treatment of disease, and will therefore also transform the nature, design, and structure of our current health care system.



Maddox

Catholic health care, with its significant investments in and commitment to providing service to all, must therefore deal proactively with the increasing and dynamic tension between its moral purpose and scientific advancement. This new science has profound implications and importance for moral and ethical thinking and ramifications for political and regulatory oversight. Thoughtful reflection and deliberate, judicious decision making at the national and international levels is needed now more than ever.

The science will continue as it should. The control and application of the scientific discovery, however, requires the involvement of every other human discipline.

Catholic health care is uniquely positioned as a provider of service, as well as a moral voice for justice, human dignity, and respect for the individual. It is also uniquely positioned as an effective and respected advocate at the national as well as state level. At this time, Catholic health care can use its voice most effectively in influencing public policy regarding genetic science. Although law, executive order, and regulations currently govern much genetic research and application, our nation continues to need dialogue and thoughtful discourse regarding the application of science, morality, and ethics, in order to reach appropriate and necessary public policy.

Such discourse is now under way in the scien-

tific, academic, and political communities. It is now time for Catholic health care to participate from a fully informed, knowledgeable, and objective perspective. In the worldwide debate and discourse regarding genomics, it is critical that Catholic health care be aware of the context of others' realities so that the ministry can be seen as a respected voice as it advocates its position, based as it is upon the moral authority of the Catholic faith.

To do so, the entire Catholic health care ministry must increase its collective awareness and understanding in order to be properly positioned and respected. And accomplishing that will require a dedicated, focused, and committed effort to build knowledge and awareness throughout the entire ministry.

**DAVID B. PRYOR, MD**

Senior Vice President, Clinical Excellence  
Ascension Health, St. Louis

A common theme throughout the articles in this series is that advances in genomic science have resulted in a significant increase in our understanding of disease. This knowledge will eventually lead to new therapeutic interventions



Pryor

for diseases that medical practice is currently unable to treat or cure. A complementary theme is that medical progress through genomic science itself is not contrary to the view of Catholic health care as a sacred trust and a healing ministry. However,

one concern associated with genomics is that some genomic interventions may not be consistent with the guiding values and principles of Catholic health care.

Indeed, if some therapeutic interventions that result from genomic progress are not consistent with the guiding values and principles of Catholic health care, the perception could arise that state-of-the-art care is not available at Catholic facilities. Our ministry could find itself challenged to counteract that misperception. While Catholic health care already may find itself defined in the public eye by what it doesn't do, Catholic health care has an obligation to act as an advocate on behalf of the *whole* person within the *healing relationship* between caregiver and patient.

A notable characteristic of modern medical

practice is that the patient is often reduced to smaller and smaller parts—organs and physiologic and biochemical systems. Genomics extends this process even further, permitting a focus on foundational subcellular systems and components. This “micro” focus can allow clinicians to better treat the patient’s disease and increase understanding of disease processes. The danger in this approach lies in failing to understand, or even recognize, the “emergent properties” of the human person suffering from illness. At the end of the first article in this series (Jeffrey G. Shaw, “An Introduction to Genetics,” *Health Progress*, May-June 2005, pp. 46-52), we were presented with the fact that 5 million strands of DNA could fit through the eye of a needle. A significant implication of genomics for Catholic health care is, then, the increasing importance of person-centered care that improves the quality of the social, spiritual, and emotional dimensions of the patient’s life, as well as the physical condition.

The articles in this series highlight the increasing importance for Catholic health care to establish a credible voice with which to participate in ongoing dialogue regarding genomic medicine. This dialogue needs to occur within both the medical and scientific community, on one hand, and with the general public, on the other. The Catholic health ministry must be one of the primary interlocutors in this discourse. In order to be that interlocutor, Catholic health care must accomplish two tasks here and now:

- First, the ministry must work together as a whole to establish a unified vision concerning advances in genomic medicine.

- Second, those of us who work in the ministry must continue to educate ourselves, our staffs, and the communities we serve regarding genomic medicine and the particular view of the sacred that shapes our response to emerging genomic technologies.

While I am convinced that dialogue is an appropriate starting point, our health ministry must also be able to show the public that we can “walk the talk.” To this end, ministry leaders must consider the potential impact of advances in genomics on where and when particular diseases are treated within the care continuum, and how, as a result of treatment, revenue streams will be affected. We must consider genomics in the design of care plans and delivery models, so that the new science can be incorporated in care practices as quickly as possible, as fluidly as possible, and to the greatest

benefit of those we serve. Strategic planning must account, to the best of the planners’ ability, for the potential shift to a more ambulatory and pharmacological-based mode of care, while remaining attentive to the acute and long-term care needs of an aging population.

We must make every effort now to fix current models, systems, and processes of care delivery and financing to create health care that is sustainable, holistic, safe, and leaves no one behind.

Perhaps in the end, the best way for Catholic health care to become known for *how* it does what it does—rather than for what it does not do—is to ensure that advances in genomic medicine do not exacerbate the existing injustices within our current system of health care.

#### **THOMAS C. ROYER, MD**

President/CEO

CHRISTUS Health, Irving, TX

Clearly, Catholic health care facilities have a unique opportunity to participate in dialogue and to apply our spiritual values and ethical principles to issues associated with genetic testing. Advances in genet-



Royer

ics will have a practical impact on health care providers and, more importantly, on those receiving care. From the Catholic perspective, we must consider two aspects of medicine and consider the benefits and ethical dilemmas concerning each.

First, genomics is playing an increasingly important role in the diagnosis, monitoring, treatment, and, in some cases, prevention of disease. These things are all beneficial and affirm the uniqueness of the individual, which is in keeping with the Catholic faith tradition.

However, as genetic tests become increasingly available, they occasion a continued debate as to the best way to deliver them to the public and medical communities, both of which are often unaware of the tests’ scientific and social implications. We who work in Catholic health care believe in social justice and equality for all; how can we ensure that data from genetic testing will not be misused and that all people are being treated fairly? Will the information gathered from genetic tests be kept private; or could it be shared, for example, with a potential employer who might discover that the person tested is

prone to cancer and, as a result, refuse to hire him or her? Might there be possible discrimination against individuals with certain genetic dispositions? Then too, although we know that some genetic tests save lives, we are still unsure how to interpret many of those tests accurately, free of the risks associated with false positive testing. For example, would HIV testing be considered public knowledge, and, if so, should employers have access to that information? Many people could suffer harm by testing false positive when they are, in reality, not afflicted.

Second, medicine that can be successfully and appropriately tailored to treat the individual may be profoundly beneficial. Again, this affirms the uniqueness of the person, a principle aligned with Catholic social teaching. However, ethical issues in this case relate to access to services and allocation of resources. Who will have access to this type of customized treatment? Will it be made accessible to all persons, or only to those with the ability to pay?

As Catholic health care providers, we need to be fully informed of the benefits and challenges related to genetic testing. We should learn as much as possible about the rapidly expanding base of knowledge in genomics, rather than basing our opinions on perspectives and assumptions that may be untrue. As difficult as it may be, we must balance the value of the knowledge we have gained (and will continue to gain) so that it benefits as many lives as possible, and does so in a way that is consistent with Catholic institutions' mission and values. We must not allow ethical concerns over a small portion of this activity to prevent us from moving forward in the age of genetics.

As for the ethical concerns posed by genetic testing, the Catholic approach must come from the traditional Catholic teachings that respect the human dignity of each person, acknowledge the importance of the common good, show special concern for the poor, and call for responsible stewardship of resources. ■

**HIT YOUR  
COMPENSATION  
TARGET  
THE FIRST TIME!**

**We provide independent executive, physician, and staff compensation consulting services to the healthcare industry.**

Atlanta 678-281-7000    New York 212-332-3288  
Chicago 312-739-2000    Westport 203-221-2823  
Detroit 313-872-1760

Toll-free 888-739-7039  
[www.sullivancotter.com](http://www.sullivancotter.com)

**sullivancotter**  
AND ASSOCIATES, INC.