

# THE GENETIC REVOLUTION: FORCE BEHIND A MORE ETHICAL HEALTHCARE SYSTEM?

**G**enetic research is having a revolutionary influence on healthcare delivery, on medical practice, and on society, Jeff C. Goldsmith, PhD, said in a recent interview with *Health Progress*. In his work as a futurist, Goldsmith looks for the forces driving healthcare changes. For years he believed the main driving forces were the organization and financing of healthcare services. Now he says, "The underlying mover is technology and the changes in medical practice that result from that."

The changes will require society to rethink its values and behaviors, says Goldsmith, who is president of Health Futures, Inc., Bannockburn, IL. "The people who are working on the Human Genome Project realize they're laying down a baseline of knowledge that will completely reshape medicine," he says. Biomedical ethics centers have begun to generate a body of critical thought about what the new knowledge will mean.

## HUMAN GENOME PROJECT

The Human Genome Project is being conducted in the United States by the National Institutes of Health and the U.S. Department of Energy. Several other countries also have genome programs. Scientists involved in the Human Genome Project are mapping the human body's chromosomes to find where specific genes are located. Their next step is decoding the genetic sequence to find out how specific genes cause a particular disease.

Goldsmith predicts that by the end of this decade, hundreds of genetic tests linked to specific illnesses will be in the hands of primary care physicians. Within 12 to 15 years physicians will be able to do a comprehensive genetic assay—"a complete snapshot"—of a person's risk of developing an inherited disease.



*Jeff C.  
Goldsmith  
Says New  
Technology  
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Care*

## USING GENETIC INFORMATION

How we will use this tool—an instrument of "astonishing power"—troubles Goldsmith. "I'm wrestling with the question myself. Of the grandparents and parents in my and my wife's families, three have died of cancer. It's already fairly clear that we inherit genes—like the P53 tumor-suppressor genes—that protect us from cancer. If I found out I had a damaged P53 tumor-suppressor gene, what would I do with that information? What would I tell my children, and when, about their potential cancer risk?"

**Insurance** One option Goldsmith could consider is protecting his children from the financial consequences of his early death by purchasing additional life insurance at a comparative bargain. For at least a period of time, he believes, insurance companies will not have access to test results. Would society ever allow insurance companies to mandate that applicants submit to genetic tests in order to individually rate them? he wonders aloud. But in the next breath, he says, "I don't think there's a chance that we'll permit that to happen, and yet, if we don't, what happens to the actuarial basis for insurance? Insurance under the current ground rules has a very cloudy future."

Goldsmith thinks community rating will become the norm, whether it happens incrementally or quickly (as a result of health reform), and insurance companies will not be allowed to discriminate on the basis of preexisting genetic conditions. "By the time this armada of genetic tools is available, community rating is going to be pretty much essential."

**Choices** But beyond the insurance question lie more troubling issues: "the issues of free will and abortion and how risk averse our society is." Within about 10 years it will be possible to subject one fetal cell to a comprehensive genetic assay to identify the unborn child's inherited dis-



ease risk. "How are people going to cope with this information?" Goldsmith asks. "Will they be tempted to abort a child with a damaged tumor-suppressor gene?"

The technology to insert new genes into the body to correct for either inherited or acquired genetic damage will be available for some illnesses within five years, Goldsmith predicts, and could have as powerful an influence on disease as antibiotics have had. After decades of searching, researchers are closing in on the causes of cancer as a result of genetic research. "A picture of the disease's genetic and molecular roots has snapped into focus in the past three years."

Genetic therapies can alter either the germ line (what is reproduced in the gene pool) or somatic mutations (which are not necessarily inherited). Altering the germ line affects all subsequent generations, whereas correcting for somatic mutations changes only the individual's genetic make-up.

Goldsmith conveys a certain urgency about addressing ethical issues. "We are going to have a critical shortage of genetics counselors in a very short period of time, and the priesthood is going to have to become genetically literate."

### THERAPIES FOR CHRONIC DISEASE

Genetic therapies, which promise to reduce morbidity and mortality from many conditions, further the advances against infectious disease already made in this century. "We have traded mortality from infectious disease for increases in life expectancy and rising mortality from chronic disease," Goldsmith notes.

Most of the diseases that bring people into hospitals today are chronic diseases that have genetic roots—heart disease, cancer, mental illness, degenerative diseases of the central nervous system such as Alzheimer's. "When you read in the newspapers that a firm genetic

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association with a particular illness has been established, you should really read two consequences," he says. "The first is the ability to predict with far greater precision than we can today the likelihood that an individual will develop that illness." Second, clues to the specific chain of events that leads to the disease are uncovered once it is clear that a genetic defect causes or is associated with that disease.

### HEALTHCARE DILEMMA: CHANGE OR CONTINUE?

Goldsmith predicts that the latter consequences will provide "a cornucopia of therapeutic options" for chronic diseases that will allow people to live longer. As a result, pressure on society is rising: Will we insist on healthcare policies that improve the health status of the elderly or continue current policies that favor treating the symptoms of acute illness but create an ever-lengthening period of disability?

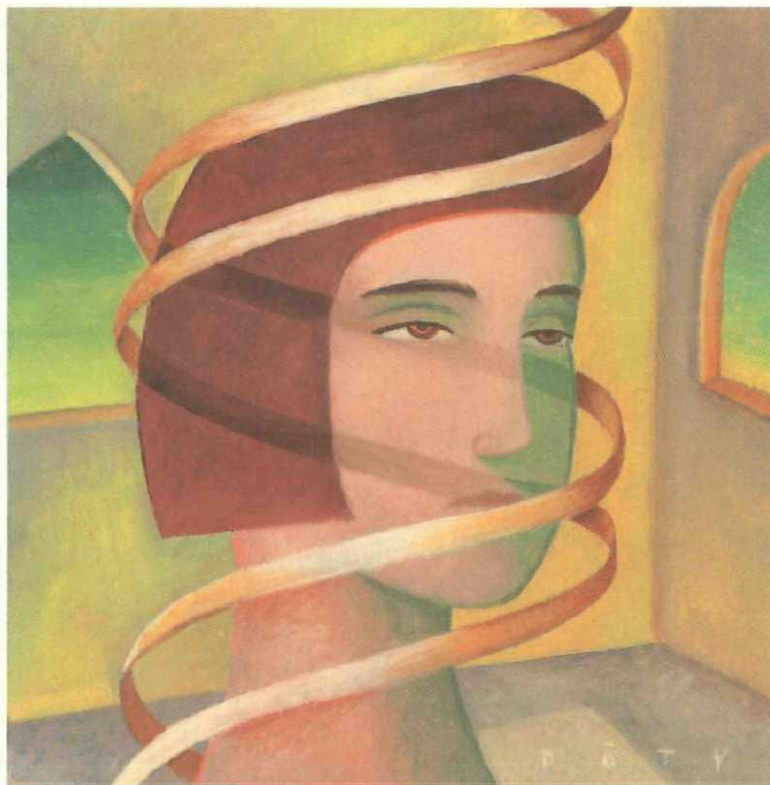
Goldsmith hopes the country will opt for a healthcare system that "compresses morbidity" so that people have a long period of health followed by a short period of catastrophic decline. He deplores the "perverse" financing incentives that favor acute care over prevention. "Such incentives are inexcusable in an era of genetically based prediction."

### ACUTE CARE'S FUTURE

Continuing the acute care system as the "central architecture" of the twenty-first century will not be tenable, according to Goldsmith. "We won't need a million hospital beds; we *will* need an extensive cadre of community-based clinicians—physicians and nonphysicians—armed with an armada of new tools, as well as preventive therapies."

Reform proposals like the Catholic Health Association's, which stress integrated delivery networks, are a source of hope because they would replace an "obsolete architecture" of healthcare financing and

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Curt Doty



## GENETIC REVOLUTION

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delivery with an "architecture grounded in pushing resources out into neighborhoods." Goldsmith applauds the proposal's anticipation of a rearrangement of healthcare spending priorities so that keeping hospitals full is no longer at the top.

But he expects an evolutionary, rather than revolutionary, change in the system. "It's going to take a generation to change the goal structure and values of healthcare executives and practitioners. You can't expect people who have grown up in an acute care matrix to say, 'What I learned to do is no longer relevant.'"

### AN EXCITING FUTURE

In spite of frustration at the pace of change, Goldsmith is "tremendously excited" about the future of healthcare. "We are headed toward a point where we will have the tools to improve the health status of a population of people—to convert what were viewed as unavoidable acts of nature into something we can manage as a society." This ability will ultimately be more satisfying for healthcare managers and for sponsors, he believes. "To be able to engage communities in improving their own health status, and in avoiding catastrophes, resonates more with the values that brought them into healthcare."

—Judy Cassidy

## CHANGING THE WAY WE CARE FOR THE DYING

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ventions. Policy development must include vigorous educational efforts to help physicians, nurses, and others realize that dying is a natural part of living and efforts to overcome death should be guided by reason.

Dying persons should not be assaulted relentlessly with technologies to the extent that they are forced to die one organ system at a time. Rather, healthcare professionals should understand that the proper use of life-prolonging measures often requires forgoing efforts to sustain life while the person remains able to experience dying as a personal reality. Institutions must provide settings conducive to such an experience. Transforming a sterile and oppressive technological environment into a place where families feel welcome and patients experience comfort and solace may require both creativity and a commitment of additional resources.

Second, Catholic-sponsored long-term care givers need to overcome the troubling tendency to transfer dying persons to acute care facilities when death is imminent. Ethics committees and pastoral care and ethics education personnel must address the attitudes, fears, and lack of understanding that lead such care givers to distance themselves from patients' deaths. These facility personnel should also educate care givers so they understand the ethical distinction between killing and allowing a person to die by withholding or withdrawing life-sustaining interventions. Moreover, ethics committees and pastoral care and ethics education personnel need to help care givers and families understand that when it is appropriate to allow death to come, they have a unique opportunity to accompany dying persons on the journey toward new life.

Third, hospice services should be available and their use encouraged. Physicians familiar with hospice should educate those who are not in hospice goals and practices. Physicians and other care givers need to support dying

persons and their families in their interest in using hospice, rather than chastising them for "losing hope." Where possible, acute and long-term care administrators should develop hospice services under Catholic sponsorship to ensure that the insights of the faith tradition with regard to dying, death, and resurrection are an integral part of the way care is rendered.

Finally, representatives from Catholic healthcare should work with parishes to encourage the faith community to share in the responsibility of providing home care for dying persons. This may be as simple as regularly visiting with family care givers to offer support. It may mean providing respite time for family members or providing some meals or housekeeping services. It will always require the prayerful support of the parish community as it witnesses in faith to the promise of resurrection and new life.

Dying persons are among the most vulnerable members of the human family. The moral health and integrity of the broader community can be measured in part by the way we respond to their needs. As we anticipate more appropriate healthcare services in the future, let us not neglect to reform the way we care for the dying. □

### NOTES

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