

# Chairman's Summary of the Conference

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## **The Implications of the New Genetics for Health Professional Education**

In October 1998 the Josiah Macy, Jr. Foundation convened a conference on the rapid rate of change in genetic knowledge and the growing need to incorporate a genetics perspective into medical education.

The mapping of the human genome is scheduled for completion by 2003, just a few short years away. Already the advances in medical genetics and the flood of new information from this ambitious project are forcing fundamental changes in the ways we think about health and disease and in the way medicine is practiced. Today's changes are only a beginning. Medicine as we know it, with its emphasis on disease and treatments, is being replaced by a new focus on sustaining and optimizing health.

While it may be years, even decades, before much of the new genetic information can be fully translated into daily medical practice, the impact is already being felt. Reports of new genes linked to specific conditions have become a daily occurrence. With each new report, it becomes increasingly clear that genetic disorders are not simply rare, single gene disorders. Instead, all disorders have a genetic base that may involve not one but many genes interacting in different environments to increase or decrease the risk for disease.

If this is true, genetic medicine is no longer the sole domain of the geneticist. All physicians will need to understand genes and gene interactions simply to manage patients with common, everyday disorders. Already physicians are confronting this new challenge. Worried patients now elect to undergo expensive commercial tests for specific gene mutations, even before it is precisely clear what the

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results mean. Too, patients are regularly bombarded by genetic "information," through the media, the internet, support groups and advertising, forcing physicians to help them sort through the information to determine what is valid and what is misleading or inaccurate.

The challenge to physicians promises to be even greater as the flood of genetic information increases. Eventually physicians will be able to use genetic information, encoded on a small and inexpensive chip, to predict a patient's risk for given problems and advise how those problems might be avoided. When disease does occur, a second chip will provide a guide to more precise diagnosis and customized drug or gene therapy.

But, as these promising prospects materialize, physicians will need exquisite sensitivity to the ethical problems inherent in the new genetic medicine, and an awareness of the damage that can be caused by misuse or misunderstanding of genetic information. They will also need to help patients grasp the fundamental notion that risk is not certainty and that lifestyle and environment can play important roles in minimizing or enhancing any risk.

These impending changes all point to the need to prepare future physicians to meet both the known and the unforeseen challenges of the new genetics. Recognizing the growing need to incorporate a genetics perspective into medical education, the Josiah Macy, Jr. Foundation, in keeping with its long-standing commitment to the education of health professionals, convened a conference in the fall of 1998 to consider "The Implications of Genetics for Health Professional Education." Dr. Leon Eisenberg, Presley Professor of Social Medicine at the Harvard Medical School, served as chairman.

Prepared presentations covered a spectrum of issues, from a progress report on the Human Genome Project at the National Institutes of Health and an ongoing effort to develop a genetics-based medical school curriculum to an examination of the compelling ethical, legal and social issues raised by the new genetics. Even though genetics is gradually entering into the curriculum of many medical schools, it was evident from the presentations that simply adding a course or two will not be sufficient. Instead, the philosophy behind medical education will need to shift to reflect the changes already being forced by the growing wealth of genetic information.

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In his eloquent keynote address, entitled “Medicine Through a Genetic Lens,” Dr. Barton Childs, professor of pediatrics at the Johns Hopkins School of Medicine, propounded just such a philosophy by calling for a shift in medical thinking, especially among the faculty who will teach the coming generations of physicians. “I am not asking for a change in curriculum,” he assured participants. “I am asking for a change in ideas, a different point of view, a change in how people think.”

Simply stated, his “genetic lens” would refocus medicine away from specific disease back to the individual patient. Today’s medicine, successful as it has been, takes a mechanistic approach. The concept of the body as a machine that needs to be fixed invites expectations of a “magic bullet” solution. Patients want to be told what’s wrong and be given something, whether medicine or treatment, to fix the problem quickly without a change in diet or lifestyle. The approach also has some appeal to physicians under growing managed care pressures to expedite care and spend less time with individual patients. “The perspective focuses on the ‘classic case’ as if a disease were the same in each person, failing to consider that no two diseases are the same because of individual differences in predisposition and susceptibility, exposure and experience,” Dr. Childs explained. The body as machine metaphor will continue to be useful, but “it is by adding diversity to the metaphor of the machine that genetics adds significantly to how we think about disease.”

The “genetic lens” will move medicine from asking only what disease and how to treat and will be used to answer the different, but crucial, questions of why disease occurs in an individual, why a given disease occurs at a given time, and most importantly how health can be restored in that individual. Knowledge of specific characteristics can then be used to maintain health and prevent disease. Adopting this perspective will produce a change in medical thinking. The patient will be viewed not as a “case” but as an individual who, because of specific genetic predispositions, environmental exposures and development, has developed disease.

The shift in how the profession views disease is taking place, but slowly, as is typical with any significant change in the conceptual basis of a profession. To speed the process, Dr. Childs suggests, “it is time for formal action to incorporate into medical education the new ideas generated by a penetrating understanding not only of the structure of genes, but of their origin in evolution and the functions

of their products in human homeostasis and disease.” As for the impact on medical education, he believes the challenge is “to organize our thinking to give students the intellectual equipment to adapt to the diversity of changes that are upon us.”

A perspective similar to the one Childs espoused is about to be put into practice at the Medical School at the University of Vermont. There, with the full support of the dean, members of a dedicated task force are redesigning the entire medical curriculum to reflect the belief that medical genetics is changing the way medicine is practiced and that future physicians need to be trained accordingly. They argue that a genetics-based framework would shift attention from a disease-based approach to a health-based prevention model of health care.

The task force has laid the groundwork for an innovative curriculum that will assure that future physicians integrate genetics, epidemiology and ethics into their practices. Those three disciplines provide the base around which the entire curriculum is organized. The new curriculum — known as GEE for lack of a better acronym — sets a new foundation for teaching medicine. The three are taught as a single topic, initially as a first year course, then as a theme that is carried through in tutorials, in the clinical years and in the senior selective year. By building these topics into courses, students will understand they are issues with which they will have to contend as physicians, not just a course they need to get through, the team believes.

The basic philosophy behind the GEE combination recognizes first that the interplay between genetic factors and environmental factors is important to all human health and disease. The combination of genetics and epidemiology then allows a study of disease by age, gender, socio-economic status and ethnicity which will, in turn, help reverse misconceptions about disease distribution in minority groups by relating humans according to genes and environment, not appearance or skin color. Ethics was added because of what curriculum designers foresee will be inevitable ethical dilemmas arising from the study of the variability of genetic makeup and the distribution of genes in different environments. The implications will place a considerable burden on physicians as they consider the ethical implications of their advice, diagnoses, and treatment recommendations.

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Rather than trying to teach a full body of knowledge in all areas, the new University of Vermont College of Medicine (UVM) curriculum is competency-based. Core skills and sets of knowledge that must be mastered in order to practice medicine have been identified for the students. In addition to telling students what must be mastered in each area before they move on, the new curriculum tells them how to go about learning the material, provides them with computerized assisted teaching programs and equips them to measure and map their own achievement of competency skills and attitudes. That means information technologies play a vital role. UVM is constructing a model for an online, filtered set of medical science facts and teaching tools to a learner-focused teaching. Teaching tutorials track student progress through the curriculum.

The new curriculum is about to be implemented at Vermont. The school is proposing rigorous and ongoing assessment and evaluation. Competencies of students will be measured through examinations, standardized patients, performance on the medical licensing examination, and interviews; faculty tutors will observe skills and attitudes that are difficult to measure.

With both a philosophy and a teaching method based on that philosophy to consider, conference participants also learned of efforts at the University of Washington and the University of Michigan Schools of Public Health to incorporate genetics into the curriculum, using knowledge from human genetics to improve public health and prevent disease.

A recent American Medical Association (AMA) survey of practicing physicians identified genetics as an area where continuing education programs are needed. The Human Genome Project at the National Institutes of Health has launched several programs to address the need for professional education. These include a continuing education program aimed at disseminating genetics information to practicing nurses, a project to export programs, like the one at the University of Michigan, so they can be adapted or used by other institutions; a World Wide Web program to introduce primary care physicians to genetic counseling; and Genline, a new electronic clinical genetics knowledge base which, in years to come, is expected to become an important resource for all health professionals.

The Human Genome Project along with the AMA and the American Nursing Association, with the backing of the Robert Wood Johnson

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Foundation, has also been instrumental in setting up a coalition of more than 100 different health professional organizations. The coalition has the stated goal of promoting health professional education and access to information about advances in human genetics. Members plan to develop core competencies in genetics for all health professionals, encourage journals to publish more genetics information, and push to integrate genetics into licensure and certification procedures, as well as develop the tools, such as a web-based resource of information on genetics and genetics education, that will speed the integration of genetic knowledge into existing practices.

In addition to the potential of the new genetics, participants were alerted to the downsides and risks. These, too, have implications for educating the future generation of professionals. A richer understanding of health and prevention could be undermined by narrow and simplistic uses of the information that will make social problems that have long existed even worse. In that sense, the new genetics could prove the proverbial double-edged sword, for the more glamour genetics gets from its new power, the more risk it poses for invasion of privacy, discrimination, reinforcing persistent racist views, or using information on genetic predispositions to weed out weaker or more susceptible human beings.

In terms of ethical issues, participants were reminded, genetics raises nothing new. It simply raises all issues at the same time. Future physicians, for example, will have to grapple with informed consent, through a "genetic lens." Genetic information is complex, involving not only the genetic information on the promised computer chip but calling into play probabilities and assessments of lifestyle, current health, age and stage of life, and life experience, all against a background of profound misunderstanding and belief that genetics either determines everything or nothing. From a practical standpoint, the question of payment for the time needed to provide full details of informed consent in individualized medicine needs careful attention at a time when budgets for medical care are under tight scrutiny.

The prospect of wide genetic testing has already prompted fears about how the information could be used to discriminate against those with certain susceptibilities, either to restrict or even deny insurance coverage. Many people have already vowed not to submit to tests if insurers were allowed to discriminate. Some states already prohibit use of such data and many insurers have asserted they would not use the results of genetic tests, relying on information

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from physician records, data bases and their own examinations. Even so, public concerns about the potential misuse of information have had the net effect of eroding public trust.

A better grounding in genetics would eliminate the misuse of race as though it were based on biology. In medicine, genetic diseases too easily become racial diseases. Race has been used as a proxy for biology or genetic differences. In fact, there is no consensus on a biological definition of race which was once used to justify slavery, anti-immigration laws and segregation. What purpose is served by identifying a patient with a broken ankle as black or caucasian, participants were asked, or in classifying as "black" a child with one black and one white parent? The new genetics should prompt a more sophisticated view of human variation and individual differences, and eliminate the notion that skin color is short hand for genetic variation.

Participants were reminded that in the past, perceived genetic differences were used to justify social and political goals. Though usually associated with Hitler and Nazi Germany, eugenics has a long history dating back to the 19th century but more recently was carried out between 1930 and 1970 in Sweden when some 60,000 people were legally sterilized to reduce the chance of children with genetic disorders. Though unlikely to recur on such large scale, the prospect of using genetic information to produce babies expected to be more intelligent, athletic or better behaved could lead some families to practice eugenics on an individual basis.

Participants were also confronted with the realities, and difficulties, of effecting change in medical education. Overcrowded curricula, overextended faculty, and lack of resources are typical excuses. Change of the kind we want to encourage is usually inspired by wide dissatisfaction with the status quo and will require effective leadership and the enthusiastic participation of faculty members.

Among the ingredients needed to foster the necessary change in perspective, participants agreed, are wide exposure of the "genetic lens" proposal and dynamic leadership from deans of leading medical institutions. Given their vision and creativity, the nation's medical schools will find their own solutions for meeting the educational challenges posed by the new genetics, they acknowledged. It would, however, speed the process, participants agreed, if existing prototypes and models were widely available to stimulate thought and activity.

**To underscore their conclusions, participants agreed upon the following statement and consensus recommendations:**

The explosive growth of knowledge about human genetics and its powerful implications for the treatment and prevention of disease demands the transformation of medical education. A genetic point of view is not something to be added to an already crowded curriculum, but a new way to think about illness and to interact with patients that must be incorporated into all teaching. As this report points out, it has the potential of enabling doctors to individualize care in a way never before possible. Physicians who bring a genetic perspective to clinical practice will be able to custom design programs of prevention and treatment which consider the health status of each patient as a unique outcome of the interaction between genes, development and environment, with roots in the past and potent implication for possible futures. These goals will not be achieved until medical schools use the new genetic knowledge to refocus medical education so that physicians in all specialties view their work through the new genetic/developmental/environmental lens.

The past history of the misuse of pseudo-genetics as a tool for discrimination and the possibilities of the new knowledge for targeting individuals demands that the new curriculum fully address the social, economic, legal and ethical issues that arise from genetics. Because the preparation of physicians to deal with genetics already lags (patients confront them daily with requests to explain the implications of genetic findings), the goal of reformatting medical education to reflect this new point of view should be given considerable urgency.

Therefore, we recommend that the American Association of Medical Colleges and the Council of Deans take steps to ensure that "a genetic point of view" is incorporated into all levels of medical education. No one model will fit all schools; therefore, faculty planning groups should tailor their efforts to the individual missions and characteristics of their institutions. We do, however, suggest that the prototype genetics/epidemiology/ethics curriculum being developed at the University of Vermont College of Medicine be circulated among faculty curriculum planning committees at other institutions. As data become available on its effectiveness in meeting its goals, that information should be widely distributed.

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Because faculty are key to the success of change, members should be fully involved in constructing new curricula. At the same time, medical school deans and their curriculum officers should spur the effort to incorporate a genetic point of view into medical education.

Public health, nursing and allied health professional education programs should adjust their curricula to reflect the new perspective. Prototype teaching programs in public health have been designed by the University of Michigan and the University of Washington. As data on their effectiveness become available, those data should be carefully monitored.

The American Medical Association should be encouraged to incorporate a genetic perspective into its medical education programs. We applaud its participation in the National Coalition for Health Professional Education in Genetics, and other professional associations in the field should be enlisted to participate in the effort to disseminate the new understanding of health and disease.

# Participants at the Conference

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