

THE WHITE HOUSE

WASHINGTON

April 4, 1994

Janet D. Rowley, M.D.
President
The American Society of Human Genetics
9650 Rockville Pike
Bethesda, Maryland 20814-3998

Dear Dr. Rowley:

Thank you for writing in support of the Administration's efforts to guarantee that all Americans have health insurance coverage.

Since the Lasker Award ceremony, I have continued to think about the connection between advances in human genetics and the need to prevent insurance companies from excluding individuals with preexisting conditions. As you so correctly note in your letter, the rapidly increasing identification of genetic predispositions to a wide range of illnesses makes the elimination of pre-existing condition exclusions absolutely essential.

Thank you again for your support and ongoing contribution to the debate on national health reform.

Sincerely yours,


Hillary Rodham Clinton

cc: Francis Collins, M.D., Ph.D.

THE AMERICAN SOCIETY OF HUMAN GENETICS

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October 7, 1993

First Lady Hillary Rodham Clinton
The White House
1600 Pennsylvania Ave.
Washington, D.C. 20500

Dear Mrs. Clinton:

As presidents of organizations representing almost 7,000 health care providers and researchers in the field of human genetics, we are writing to express strong support for your comments at the Lasker Award ceremony describing the emerging connection between Health Care Reform and advances in human genetics. The time is rapidly approaching when many individuals will have risks of future disease identified by DNA testing. Our present health insurance system often leaves these individuals without coverage, just when it is most needed to allow preventive and potentially lifesaving measures. A revolution is underway in our understanding of disease etiologies, catalyzed by the Human Genome Project and associated breakthroughs in genetic technology. The precise identification of the genetic basis of cystic fibrosis, Huntington's disease, acute leukemia, and many other conditions leading to serious mental and/or physical disability has been achieved. Immediate improvements in accurate diagnostics have already occurred and better treatments are eagerly anticipated.

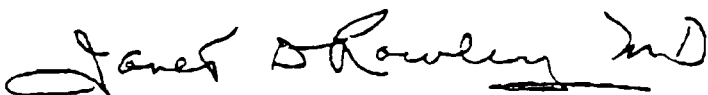
Of even broader significance for the nation's health is the imminent identification of major genes responsible for common diseases such as breast, ovarian, and colon cancer, diabetes, and manic depressive illness. These advances offer, for the first time, the potential of identifying personal risks for future illness, allowing development of those individually-designed preventive measures (life style alterations and/or medical surveillance) to focus our health care resources on staying well. This is the very essence of preventive health care.

As your insightful remarks indicate, however, the ability to identify genetic risks for common disease in a large fraction of the population carries major consequences for health care insurance. If nearly everyone is found to have a genetic predisposition to one or more illnesses, who will be insurable? We believe that these developments, which are only a few years off, represent a strong argument for revamping the U.S. system now to provide universal health care coverage. We applaud the Clinton administration, and you personally, for initiating these bold steps. Collectively our organizations represent a significant ally

in the articulation of these concepts to the public. We would welcome the opportunity to work with you on such an effort. Our distinguished members Nancy Wexler, Ph.D., one of the 1993 Lasker recipients, and Francis Collins, M.D., Ph.D., Director of the National Center for Human Genome Research of the National Institutes of Health, would be particularly appropriate contacts and spokespersons.

We congratulate your vision in identifying these important issues, and look forward to opportunities for our professional societies to provide a useful voice in the Health Care Reform debate.

Sincerely,



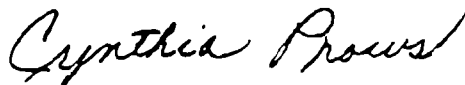
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David L. Rimoin, M.D., Ph.D.
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Karen Greendale, M.A., C.G.C.
President, National Society of Genetic Counselors



Cynthia Prows, M.S.N., President, International Society of Nurses in Genetics



Thaddeus E. Kelly, M.D., Ph.D.
President, American Board of Medical Genetics



Ann P. Walker, M.S., C.G.C.
President, American Board of Genetic Counseling

Enclosure: Statement of the Council of Medical Genetics
Organizations (COMGO)

cc: Donna Shalala, Secretary, HHS