

Board Chair, Linda Lake's Opening Remarks

"Good morning. I'm Linda Lake, Chair of the Washington State Board of Health. I want to welcome you here today on behalf of:

- Governor Gary Locke;
- State Supreme Court Chief Justice Richard Guy;
- State Department of Health Secretary Mary Selecky;
- DSHS Secretary Dennis Braddock;
- Insurance Commissioner Deborah Senn; and
- Dean Patricia Wahl of the University of Washington School of Public Health and Community Medicine -- Institute for Public Health Genetics and Center for Ecogenetics and Environmental Health

I am truly honored by all of these leaders' willingness to commit their organizations to work with the State Board of Health's partnership with the March of Dimes to sponsor today's event: Learning to Live with the Human Genome: Well Reasoned Prudence or Future Shock?

It was not even 50 years ago that Watson and Crick announced their discovery of DNA with what may turn out to be the greatest understatement of all time. "This structure has novel features, which are of considerable biological interest."

An understatement, to be sure, and one that must have appeared in a professional journal, because that kind of careful prose would never make it anywhere near USA Today, let alone on TV or radio.

But President Clinton did make all the papers last June when he described the near complete map of Watson and Crick's discovery as "the most important, most wondrous map ever produced by human kind."

So much has happened in those intervening years. More than 1,000 researchers across no less than half dozen disciplines and across six nations have revealed nearly all three billion letters of our genetic code. This is truly a stunning and humbling achievement. It is not an overstatement to say we are learning the language in which the gods created life.

What President Clinton in his statement celebrated was the very real probability that this profound new knowledge will give us immense, new power to heal. He told us genome science will revolutionize the diagnosis, prevention, and treatment of human disease.

He told us doctors increasingly will be able to cure diseases like Alzheimer's, Parkinson's, diabetes, and cancer by attacking their genetic roots. He told us of clinical trials in which some forms of leukemia and breast cancer already are being treated with drugs that precisely target the faulty genes and cancer cells, with little or no risk to healthy cells. And he suggested to us that our children's children may know the term cancer only as a constellation of stars.

Last spring, Francis Collins, Director of the Human Genome Project, told a Congressional Budget Committee, "At the beginning of the new millennium, genetics has come to encompass nearly every aspect of health research and...will enhance our concepts of shared humanity, regardless of racial or ethnic identity."

Last summer, Celera President, Craig Venter announced his company had sequenced the genome of three females and two males, who identified themselves as Hispanic, Asian, Caucasian, or African-American, and their genomes contained no way to tell one ethnicity from another. When life is reduced to its very essence, we find that we have many genes in common with every species on Earth, and that knowledge that genomic research is providing the world will have a profound impact on the human condition, not only for the treatment of disease, but on our view of our place in the biological continuum.

With world political leaders and the very top echelon of the world's biomedical research community making such statements, there should be great celebration. And yet a CNN-Time poll last summer reported that 46 percent of Americans polled believed that the impact of the Human Genome Project will be negative. Why?

The answer to this question is exactly the sobering realization that motivated state leaders to join forces to sponsor our conference today. We all know there is a very large, open question here. It is as British Prime Minister Tony Blair said "...as humanity, [are we going] to engage in the right cooperation...so that we shape our destiny in a way that genuinely does benefit all our people, that makes the most of the possibilities, and faces up to the challenges and the dangers that (the genetic revolution) poses?".

The truth is we have opened what Dr. Collins calls "God's Book of Life" at a moment of dangerously low trust in our public institutions and even in our most sacred systems of faith.

The task for us now is to outpace our computers as they race to unlock the meaning of the genetic code with the development of ethical, moral, and spiritual tools to direct the power of the genetics revolution toward the furtherance of our highest values.

The first step in that endeavor is to engage in complete, accurate, honest, and up-to-date communication with one another about what our scientists now know, what it may allow us to do, and how we value those possibilities. And it is that process I hope we can advance today. We may just move it forward a bit. Lee Hartwell and Paul Billings will educate us on the latest marvels, fears, and

policy efforts to shape our futures through genetics. And our panelists will share with us their discoveries, insights, hopes, and fears about:

- both the good and the harm that can come of the vigilant protection of our genetic privacy;
- the potential for genetic based discrimination in employment, healthcare, and other areas;
- obligations healthcare providers who know our patients' genetic codes will have;
- new computer technologies that may make the use of genetic information in diagnosis and treatment commonplace;
- how our system of legal protections and private property rights affect and are affected by the genetics revolution;
- how genetics may combine with environmental factors to improve or threaten our health; and
- how genetic information may permit us to determine not only our concepts of marriage, family, kinship, and race, but the very nature of humanity, and indeed all forms of life.

But until we have oriented, educated, and supported all of our population in integrating the truly mind-boggling developments that are the genetics revolution, we will not have completed the task we have all come here to begin. For that, we will need all of your efforts, those of your colleagues in medicine, public health, business, and the law and all of those of a responsible media over the coming decade.

As we do this, the glowing rhetoric and unbridled optimism of our research leaders, our journalists and our political leaders may actually create our greatest challenge - that of managing unrealistic expectations. As grand as our mapping of the human genome is, in the final analysis it may result in both more than we can imagine and less than we fear.

As it turns out, each of us will learn to live with our knowledge of the human genome in his or her own way. For my part, I believe President Clinton was right when he said, "we must not shrink from exploring that far frontier of science. But as we consider how to use new discovery, we must also not retreat from our oldest and most cherished human values. We must ensure that new genome science and its benefits will be directed toward making life better for all citizens of the world, never just a privileged few.

As we unlock the secrets of the human genome, we must work simultaneously to ensure that new discoveries never pry open the doors of privacy. And we must guarantee that genetic information cannot be used to stigmatize or discriminate against any individual or group.

Increasing knowledge of the human genome must never change the basic belief on which our ethics, our government, our society are founded. All of us are created equal, entitled to equal treatment under the law...Modern science's discovery of the remarkable similarity of all human genomes has confirmed what we first learned from ancient fables. The most important fact of life on this Earth is our common humanity."

Before I introduce His Honor Chief Justice Richard Guy and ask him to add his remarks to our welcome this morning, I want to take a moment to thank several of the people most responsible for the good old fashioned hard work it took to bring us all together today. The conference probably would not have occurred except for the naiveté of an intern in the University of Washington's Public Health Genetics Program, and the predatory instincts of some long time state government employees.

Ms. Miriam Fay approached Debra Doyle and Don Sloma last spring with an interest in learning a bit more about how public health policy is developed. A paper turned into a conference, and a summer internship turned into a yearlong obsession. The result is before you today. Sorry for your trouble, Miriam and thanks.

The conference was planned with the help of an informal steering committee composed of people from each of the sponsoring agencies and included Chief Justice Richard Guy, Don Sloma, Debra Doyle, Bill Hagens, Cindy Watts, Asha Singh, and Rachel Hein. Financial sponsorship was provided through the good offices of Dennis Braddock and Linda Rolfe at DSHS and their Division of Developmental Disabilities and Deborah Senn and Bill Hagens at the Office of the Insurance Commissioner. The lion's-share of the real work of producing and mailing conference announcements, taking registrations, and organizing today's event fell to the able staff at the Department of Health's Genetics Services Section. The credit there goes to Stacy Eaves, George Zimmerman, and Sarah Forker with the financial and personal assistance of the March of Dimes and the efforts of Rachel Hein.

And now, I want to introduce you to the man whose vision and determination to begin a dialogue on this issue in our state inspired us all, the Honorable Chief Justice Richard Guy, of the Washington State Supreme Court."