June 25, 2000

PRESIDENT CLINTON ANNOUNCES THE COMPLETION OF THE FIRST SURVEY OF THE ENTIRE HUMAN GENOME Hails Public and Private Efforts Leading to This Historic Achievement

THE WHITE HOUSE

Office of the Press Secretary

For Immediate Release June 25, 2000

PRESIDENT CLINTON ANNOUNCES THE COMPLETION OF THE FIRST

SURVEY OF THE ENTIRE HUMAN GENOME

Hails Public and Private Efforts Leading to This Historic Achievement

June 26, 2000

Today, at a historic White House event with British Prime Minister Tony Blair, President Clinton announced that the international Human Genome

PDF created with pdfFactory trial version www.pdffactory.com

Project and Celera Genomics Corporation have both completed an initial sequencing of the human genome -- the genetic blueprint for human beings. He congratulated the scientists working in both the public and private sectors on this landmark achievement, which promises to lead to a new era of molecular medicine, an era that will bring new ways to prevent, diagnose, treat and cure disease. The President pledged to continue and accelerate the United States' commitment to helping translate this blueprint into novel healthcare strategies and therapies. He will underscore that this genetic information must never be used to stigmatize or discriminate against any individual or group. Our scientific advances must always incorporate our most cherished values, and the privacy of this new information must be protected.

DECODING THE HUMAN GENOME WILL LEAD TO NEW WAYS TO PREVENT, DIAGNOSE, TREAT, AND CURE DISEASE. Alterations in our genes are responsible for an estimated 5000 clearly hereditary diseases, such as Huntington's disease, cystic fibrosis, and sickle cell anemia, and influence the development of thousands of other diseases. Before the advent of the Human Genome Project, a joint project of HHS, DOE, and international partners in the United Kingdom, France, Germany, Japan, China, connecting a gene with a disease was a slow, arduous, painstaking, and frequently imprecise process. Today, genes are discovered and described within days. For example, in 1989, scientists found the gene for cystic fibrosis after a 9-year search; eight years later, largely because of the coordinated efforts of the Human Genome Project, a gene for Parkinson's disease was mapped in only 9 days. Now, scientists will be able to use the working draft of the human genome to:

* Alert patients that they are at risk for certain diseases. Once scientists discover which DNA sequence changes in a gene can cause disease,

PDF created with pdfFactory trial version www.pdffactory.com

healthy people can be tested to see whether they risk developing conditions such as diabetes or prostate cancer later in life. In many cases, this advance warning can be a cue to start a vigilant screening program, to take preventive medicines, or to make diet or lifestyle changes that may prevent the disease.

* Reliably predict the course of disease. Diagnosing ailments more precisely will lead to more reliable predictions about the course of a disease. For example, a genetic fingerprint will allow doctors treating prostate cancer to predict how aggressive a tumor will be. New genetic information will help patients and doctors weigh the risks and benefits of different treatments.

* Precisely diagnose disease and ensure the most effective treatment is used. Genetic analysis allows us to classify diseases, such as colon cancer and skin cancer, into more defined categories. These improved classifications will eventually allow scientists to tailor drugs for patients whose individual response can be predicted by genetic fingerprinting. For example, cancer patients facing chemotherapy could receive a genetic fingerprint of their tumor that would predict which chemotherapy choices are most likely to be effective, leading to fewer side effects from the treatment and improved prognoses.

* Developing new treatments at the molecular level. Drug design guided by an understanding of how genes work and knowledge of exactly what happens at the molecular level to cause disease, will lead to more effective therapies. In many cases, rather than trying to replace a gene, it may be more effective and simpler to replace a defective gene's protein product. Alternatively, it may be possible to administer a small molecule that would interact with the protein to change its behavior. This is the strategy

PDF created with pdfFactory trial version www.pdffactory.com

behind a drug in development for chronic myelogenous leukemia, which targets the genetic flaw causing the disease. It attaches to the abnormal protein caused by the genetic flaw and blocks its activity. In preliminary tests, blood counts returned to normal in all patients treated with the drug.

TODAY'S ANNOUNCEMENT REPRESENTS THE STARTING POINT FOR A NEW ERA OF GENETIC MEDICINE. The sequence represents only the first step in the full decoding of the genome, because most of the individual genes and their specific functions must still be deciphered and understood. This research has begun, and already, tens of thousands of genes have been identified, including some related to deafness, kidney disease, breast cancer, hereditary skeletal disorders, hemorrhagic stroke and diabetes, thus advancing the work of researchers worldwide at a rate that would have impossible without these data. The Human Genome Project, which completed its version of the working draft two years ahead of schedule and under budget, will continue its longstanding practice of making all of its sequencing data available to public and privately funded researchers worldwide at no cost. Celera Genomics, which makes its sequencing data available by subscription, will also make its version of the consensus human genome sequence available to non-subscribers upon publication.

PRESIDENT CLINTON PLEDGES STRONG SUPPORT FOR GENETIC RESEARCH BY BOTH THE PUBLIC AND PRIVATE SECTORS. President Clinton reiterated the commitment of the United States to robust Federal support for basic scientific research facilitating medical application of the science. President Clinton also stated his support for a strong structure to review the medical, ethical and other issues presented by the expected new power of genetic medicine, building on the multi-million dollar investment the Human Genome Project already makes in research on the social, ethical and legal implications of

PDF created with pdfFactory trial version www.pdffactory.com

this work. He recognized that research and development by biotechnology companies will be key to the translation of human genome sequence data into useful, new healthcare products and pledged to strengthen a business environment that will spur research and development in this vital sector. The President also reaffirmed his support for patenting genetic discoveries that have substantial and credible uses. By protecting and rewarding investment in research, consistent with current law, this policy of intellectual property protection will promote rapid conversion of basic knowledge into useful applications, while at the same time allowing a maximum free flow of basic scientific information.

TODAY'S ANNOUNCEMENT BUILDS ON THE CLINTON-GORE ADMINISTRATION'S STRONG COMMITMENT TO PROTECTING PRIVATE GENETIC INFORMATION. Since 1997, the President and Vice President have called for legislation that will guarantee that Americans who are self-employed or otherwise buy health insurance themselves will not lose or be denied that health insurance because of their genetic makeup. Last winter, President Clinton signed an executive order that prohibits every civilian Federal Department and agency from using genetic information in any hiring or promotion action. This historic action prevented critical information from genetic tests used to help predict, prevent, and treat diseases, from being used against Federal employees. In addition, President Clinton has endorsed the Genetic Nondiscrimination in Health Insurance and Employment Act of 1999, introduced by Senator Daschle and Congresswoman Slaughter, that will extend these employment protections to the private sector and finish the job of helping to extend protections to individuals purchasing health insurance, begun with the Health Insurance Portability and Accountability Act.

PDF created with pdfFactory trial version www.pdffactory.com

Send the url of this page to a friend

To read pdf files, download the free Acrobat Reader software.

Last modified: Friday, January 16, 2004

Home * Contacts * Disclaimer

Base URL: www.ornl.gov/hgmis

Site sponsored by the U.S. Department of Energy Office of Science, Office of Biological and Environmental Research, Human Genome Program

PDF created with pdfFactory trial version www.pdffactory.com