

Joint Proclamation
by the Heads of Government of Six Countries
Regarding the Completion of the Human Genome Sequence

We, the Heads of Government of the United States of America, the United Kingdom, Japan, France, Germany, and China, are proud to announce that scientists from our six countries have completed the essential sequence of three billion base pairs of DNA of the human genome, the molecular instruction book of human life.

Remarkable advances in genetic science and technology have been made in the five decades since the landmark discovery of the double-helix structure of DNA in April 1953. Now, in the very month and year of the 50th anniversary of that important discovery by Watson and Crick, the International Human Genome Sequencing Consortium has completed decoding all the chapters of the instruction book of human life. This information is now freely available to the world without constraints via public databases on the World Wide Web.

This genetic sequence provides us with the fundamental platform for understanding ourselves, from which revolutionary progress will be made in biomedical sciences and in the health and welfare of humankind. Thus, we take today an important step toward establishing a healthier future for all the peoples of the globe, for whom the human genome serves as a common inheritance.

We congratulate all the people who participated in this project on their creativity and dedication. Their outstanding work will be noted in the history of science and technology, and as well in the history of humankind, as a landmark achievement.

We encourage the world to celebrate the scientific achievement of completing the Human Genome Project, and we exhort the scientific and medical communities to rededicate themselves to the utilization of these new discoveries to reduce human suffering.

His Excellency
Jacques Chirac,
President of the French Republic.

The Honorable
George Bush,
President of the United States of America.

The Right Honorable
Tony Blair, M.P.,
Prime Minister of the United Kingdom.

His Excellency
Gerhard Schroeder,
Chancellor of the Federal Republic of Germany.

His Excellency
Junichiro Koizumi,
Prime Minister of Japan.

His Excellency
WEN Jiabao,
Premier of the State Council
of the People's Republic of China.

1
" 640K
ought the answer
for anybody"
Bill Gates
1981

- email Kerry Braeman - NAS
- Liz re: computer science
- dates for BIO June 22-25

ⓧ

ⓧ

- Ellen for dinner...
- funding for Deb Weiner
- SACOTS 4/18? -

- USA today
White House DNA

✓ FDA status

- Walie's rides 4/15? Jaime → Alison Peck
- Gillian thank-you

- ? ideas on CMS

✓ ERA White Paper re: Planning

- Eric email Guidebook

Eric
Lander-

ⓧ "Big science to drive small science"
CON grp - Family Recruitment draft...

Scientific Symposium notes

- define the "race" variable for scientific discussion

most major contrib genes for Alz, heart dis.,
cancer, mental ill, Alyshei & Parkinson & asthma, etc.
will be identified next 5-10 yrs

2010 - mainstream individualized preven medicine

- predict gen tests for ~ 12 cond
- intervene to ↓ risk
- pharm in it of care for novel drugs

but...

- will access be inequitable? will health disparities persist?
- will regulatory affect legis for gen disc in place

2020 - genomic therap rev in full swing
(preceded by diagnostic swing)

BRINGING THE GENOME TO YOU
A PUBLIC SYMPOSIUM
Baird Auditorium, Smithsonian Museum of Natural History
April 15, 2003

Wylie Burke, M.D., Ph.D.

Dr. Burke is chair of the department of medical history and ethics and adjunct professor of medicine and epidemiology at the University of Washington. Her research addresses the ethical and health policy implications of genetic information. She is currently a member of the National Advisory Council for Human Genome Research. Dr. Burke received a Ph.D. in genetics and an M.D. from the University of Washington and completed a residency in internal medicine.

Francis S. Collins, M.D., Ph.D.

Dr. Collins is director of the National Human Genome Research Institute (NHGRI) at the National Institutes of Health. He oversees the Human Genome Project, an international, multidisciplinary scientific enterprise directed at mapping and sequencing the entire human DNA and determining aspects of its function. A working draft of the human genome sequence was announced in June 2000, an initial analysis was published in February 2001 and the sequence was finished in April 2003. Building upon that success, Dr. Collins is leading NHGRI's effort to use genomic knowledge to improve human health. His lab is currently searching for genes that contribute to type II diabetes.

Sir Francis Crick, Ph.D.

Dr. Crick was born on June 8, 1916, in Northampton, England. He majored in physics at University College, London, earning his degree in 1937. During the war, he worked as a scientist for the British Admiralty. In 1947 Dr. Crick went to Cambridge University to study biology, first in the Strangeways Research Laboratory, then the Medical Research Council (MRC) Unit, headed by M.F. Perutz and located within the Cavendish Physics Laboratory. He conducted X-ray diffraction studies of proteins for his graduate thesis and received his Ph.D. in 1954.

In 1951 Dr. Crick met James Watson, a new member of the Cavendish Laboratory. With two other scientists, Maurice Wilkins and the late Rosalind Franklin at King's College, London, they were responsible in 1953 for the discovery of the molecular structure of DNA. They also proposed how this structure allows the transmission of genetic information. Dr. Crick was awarded the Nobel Prize for Physiology or Medicine in 1962 with Dr. Watson and Dr. Wilkins for this research.

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neurobiology, especially the visual systems of animals, and on discovering the neural correlate of consciousness. He served as President of the Salk Institute in 1994 and 1995. He is also an adjunct professor of psychology at the University of California, San Diego.

Dr. Crick is a Fellow of the Royal Society and a member of the U.S. National Academy of Sciences. He is an Honorary Fellow of Churchill College, Cambridge, and Caius College, Cambridge, among others. His books include *Of Molecules and Men* and *What a Mad Pursuit: A Personal View of Scientific Discovery*.

Dr. Crick is a recipient of the Albert Lasker Award from the American Public Health Association, the Prix Charles Leopold Mayer of the French Academy of Sciences, and the Gairdner Award of Merit for outstanding medical research from the Gairdner Foundation. In 1992 he received the Order of Merit from the Queen of England, a lifetime honor given to only twenty-five living English people at any one time.

Harold P. Freeman, M.D.

Dr. Freeman is the associate director of the National Cancer Institute (NCI) and director of the NCI Center to Reduce Cancer Health Disparities. He serves as the director of surgery at North General Hospital in New York City and is professor of clinical surgery at Columbia University College of Physicians and Surgeons. A past president of the American Cancer Society, he is a leading authority on the relationship between race, poverty and cancer.

Vanessa Northington Gamble, M.D., Ph.D.

Dr. Gamble is associate professor of health policy and management and deputy director for training and education at the Morgan-Hopkins Center for Health Disparities Solutions at the Johns Hopkins Bloomberg School of Public Health. She is also the health commentator for National Public Radio's Tavis Smiley Show. Dr. Gamble received her B.A. from Hampshire College and her M.D. and Ph.D. in the history of sociology and science from the University of Pennsylvania.

Kay Redfield Jamison, Ph.D.

Dr. Jamison is professor of psychiatry at the Johns Hopkins School of Medicine. She is the author of *An Unquiet Mind*, *Night Falls Fast* and *Touched With Fire*, and co-author of the standard medical text on manic-depressive illness. She is chair of the Genome Action Coalition and was a member of the first National Advisory Council for the National Center for Human Genome Research. Dr. Jamison was awarded a MacArthur Fellowship in 2001.

Robert Krulwich, J.D.

Mr. Krulwich is a correspondent for ABCNEWS and reports for Nightline, World News Tonight, and other broadcasts. Since joining ABCNEWS in 1994, he has reported on developments in genetics, AIDS and economics. Mr. Krulwich is also a regular contributor to PBS, and has reported for *Frontline* on the savings and loan scandal and on campaign financing. He received his bachelor's degree in U.S. history from Oberlin College and his J.D. from Columbia University School of Law.

Eric Lander, Ph.D.

Dr. Lander is founder and director of the Whitehead Institute Center for Genome Research and a professor of biology at the Massachusetts Institute of Technology. He is one of the principal leaders of the Human Genome Project. Dr. Lander received his B.A. in mathematics from Princeton University and his Ph.D. in mathematics from Oxford University. He is a member of the National Academy of Sciences, the Institute of Medicine and the Academy of Arts and Sciences.

Kyle E. McSlarrow, J.D.

Mr. McSlarrow is deputy secretary of the Department of Energy. He oversees the nation's nuclear weapons complex program, a \$7 billion environmental cleanup program, and research programs including high-energy physics and technologies to strengthen the nation's energy and security. He also serves as the American co-chair of the United States-Russia Energy Working Group, established by President George W. Bush and Russian President Vladimir Putin. He received his J.D. from the University of Virginia School of Law.

Paul Steven Miller, J.D.

Mr. Miller is a commissioner of the U.S. Equal Employment Opportunity Commission (EEOC). He participates with the other four commissioners on the development and approval of EEOC enforcement policies, authorization of litigation and issuance of commissioners' charges of discrimination. Mr. Miller also served as a member of the interagency working group that drafted the Presidential Executive Order on Genetic Discrimination and Privacy. He received his Jurist Doctor from the Harvard Law School.

Thomas H. Murray, Ph.D.

Dr. Murray is president of The Hastings Center. He was formerly the Susan E. Watson Professor of Bioethics and the director of the Center for Biomedical Ethics at Case Western Reserve University's School of Medicine. Dr. Murray was appointed to the National Bioethics Advisory Commission from 1996 to 2001 and served as chair of the subcommittee on genetics. He is founder and past member of NHGRI's Working Group on Ethical, Legal and Social Issues.

Aristides Patrinos, Ph.D.

Dr. Patrinos is associate director for biological and environmental research in the Department of Energy's (DOE) Office of Science, where he oversees research in genomics, structural biology, nuclear medicine, global climate change and environmental remediation. He is the director of DOE's component of the Human Genome Project. Dr. Patrinos has a degree in engineering from the National Technical University of Athens, Greece, and received his Ph.D. in mechanical engineering and astronautical sciences from Northwestern University.

Cristián Samper, Ph.D.

Dr. Samper is director of the Smithsonian's National Museum of Natural History. Prior to this appointment, he was the deputy director and staff scientist at the Smithsonian Tropical Research Institute in Panama. His past research includes work in the ecology of the Andean cloud forests, conservation biology and environmental policy. Dr. Samper studied biology at the Universidad de Los Andes in Bogota, Columbia, and received his M.A. and Ph.D. in biology from Harvard University.

Hon. Louise Slaughter

Representative Slaughter, a microbiologist with a masters degree in public health, is recognized as the pre-eminent voice on genetics policy in Congress. As author of the Genetic Nondiscrimination in Health Insurance and Employment Act, she has worked closely with the National Human Genome Research Institute to educate her colleagues and the public about the ethical, legal, and social implications of the Human Genome Project. Representative Slaughter has testified before Congressional committees on genetics policy, and her views have been published in numerous journals, magazines, and newspapers.

James Watson, Ph.D.

Dr. Watson was born in Chicago, Illinois, on April 6, 1928. He graduated from the University of Chicago in 1947 with a degree in zoology. He received his Ph.D. in 1950 from Indiana University, where he worked with the microbiologist Salvador Luria; his Ph.D. thesis was a study of the effect of X-rays on bacteriophage multiplication. Shortly thereafter he completed a postdoctoral fellowship in Copenhagen as a Merck Fellow of the National Research Council.

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After leaving Cambridge, Dr. Watson joined the faculty at the California Institute of Technology, where he conducted X-ray diffraction studies of RNA. He moved to Harvard University in 1956

and was a professor in the department of biology until 1976. His major research interest during this time was the role of RNA in protein synthesis. In 1968 Dr. Watson became director of Cold Spring Harbor Laboratory (CSHL), and was named president of CSHL in 1994. As the director of the National Center for Human Genome Research at NIH from 1988 to 1992, Dr. Watson launched the worldwide effort to map and sequence the human genome.

Dr. Watson is a member of the National Academy of Sciences and the Royal Society of the United Kingdom. He has received honorary degrees from many universities, including the University of Cambridge and the University of Oxford. He is a co-author of *Molecular Biology of the Gene* and author of *The Double Helix* and *DNA: The Secret of Life*.

Dr. Watson is a recipient of the Medal of Freedom, awarded by President Ford in 1977; the Royal Society's Copley Medal in 1993, for his work on the Human Genome Project; the National Medal of Science in December 1997; the Philadelphia Liberty Medal on July 4, 2000; and the Benjamin Franklin Medal, awarded by the American Philosophical Society. He became an honorary Knight of the British Empire on January 1, 2002.



THE WHITE HOUSE
WASHINGTON

April 11, 2003

I send greetings to the International Human Genome Sequencing Consortium as you mark the successful completion of the Human Genome Project. This historic milestone is also the 50th anniversary of the description of the double-helix structure of DNA.

The American system of medicine is a model of skill and innovation and is adding good years to countless lives. The completion of the sequencing of the human genome, begins another era of medical progress. New gene-based screening tools are alerting patients when they have an elevated risk of diseases so they can take an active role in preventing them. Scientists believe many new therapies will be tailor-made to an individual's genetic makeup, resulting in fewer adverse effects. The scientific accomplishments and international collaboration of the Consortium bring hope and promise to countless individuals who suffer from disease and others at risk.

My Administration has demonstrated our strong commitment to medical research by completing a five-year doubling of the National Institutes of Health (NIH) budget to more than \$27 billion. As a result of this increase, the NIH now trains 1,500 more scientists per year and issues 10,000 more research grants than it did in 1998. This investment will help turn today's research opportunities into more of tomorrow's medical success stories.

I commend the scientists, researchers, and all others involved in the project for your tireless work to attain new scientific breakthroughs that enhance lives. Your efforts contribute to an improved system of medicine and will benefit the health and well-being of all mankind.

Laura joins me in sending our best wishes.

A handwritten signature in black ink, appearing to read "George W. Bush". The signature is fluid and cursive, with a large initial "G" and a long, sweeping underline.

108TH CONGRESS
1ST SESSION

S. CON. RES. 10

Designating April 2003 as "Human Genome Month" and April 25 as "DNA Day".

IN THE SENATE OF THE UNITED STATES

FEBRUARY 27, 2003

Mr. GREGG (for himself, Mr. KENNEDY, Ms. SNOWE, and Mr. DASCHLE) submitted the following concurrent resolution; which was considered and agreed to

CONCURRENT RESOLUTION

Designating April 2003 as "Human Genome Month" and April 25 as "DNA Day".

Whereas April 25, 2003, will mark the 50th anniversary of the description of the double-helix structure of DNA by James D. Watson and Francis H.C. Crick, considered by many to be one of the most significant scientific discoveries of the 20th Century;

Whereas, in April 2003, the International Human Genome Sequencing Consortium will place the essentially completed sequence of the human genome in public databases, and thereby complete all of the original goals of the Human Genome Project;

Whereas, in April 2003, the National Human Genome Research Institute of the National Institutes of Health in the Department of Health and Human Services will unveil a new plan for the future of genomics research;

Whereas, April 2003 marks 50 years of DNA discovery during which scientists in the United States and many other countries, fueled

by curiosity and armed with ingenuity, have unraveled the mysteries of human heredity and deciphered the genetic code linking one generation to the next;

Whereas, an understanding of DNA and the human genome has already fueled remarkable scientific, medical, and economic advances; and

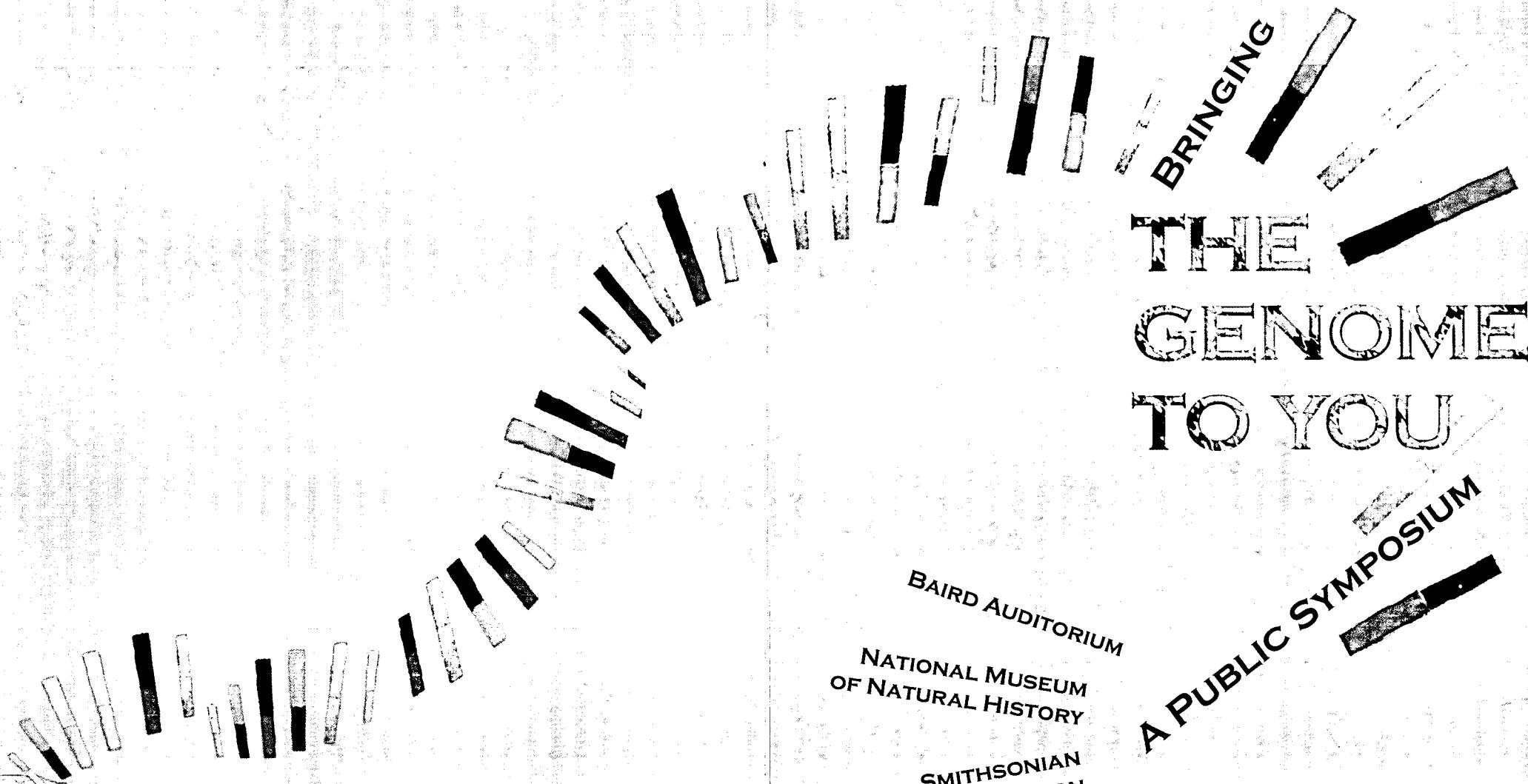
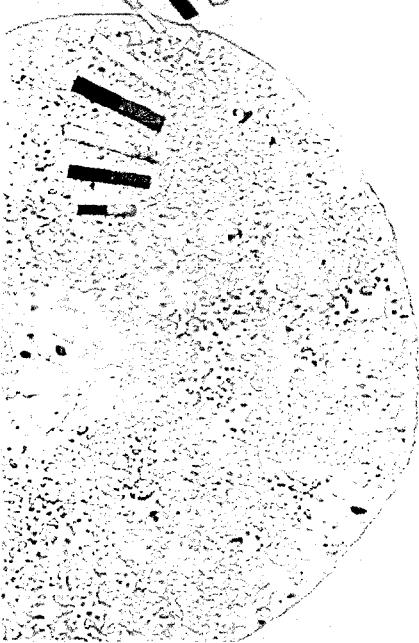
Whereas, an understanding of DNA and the human genome hold great promise to improve the health and well being of all Americans: Now, therefore, be it

Resolved by the Senate (the House of Representatives concurring), That the Congress--

(1) designates April 2003 as “Human Genome Month” in order to recognize and celebrate the 50th anniversary of the outstanding accomplishment of describing the structure of DNA , the essential completion of the sequence of the human genome, and the development of a plan for the future of genomics;

(2) designates April 25, 2003, as “DNA Day” in celebration of the 50th anniversary of the publication of the description of the structure of DNA on April 25, 1953; and

(3) recommends that schools, museums, cultural organizations, and other educational institutions across the nation recognize Human Genome Month and DNA Day and carry out appropriate activities centered on human genomics, using information and materials provided through the National Human Genome Research Institute and through other entities.

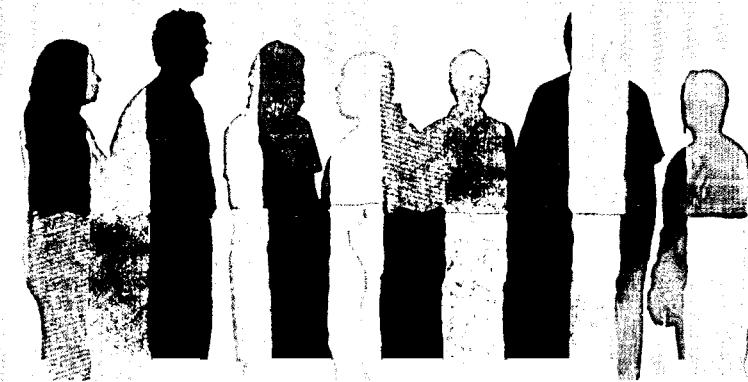


BRINGING
**THE
GENOME
TO YOU**

BAIRD AUDITORIUM
NATIONAL MUSEUM
OF NATURAL HISTORY
SMITHSONIAN
INSTITUTION
WASHINGTON, DC
9 AM - 1 PM

A PUBLIC SYMPOSIUM

APRIL 15, 2003





ACKNOWLEDGEMENTS

This event made possible by:

**National Human Genome Research Institute
National Institutes of Health
Department of Health and Human Services**

Department of Energy

**Genetic Services Branch
Maternal and Child Health Bureau**

**National Newborn Screening
and Genetic Resources Center**

**Office of Rare Diseases
National Institutes of Health
Department of Health and Human Services**

Foundation for the National Institutes of Health

and these distinguished sponsors:

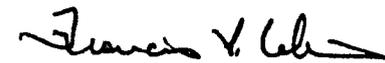
**Applied Biosystems
Fisher Scientific International
IBM Life Sciences
Pfizer Inc**

**GlaxoSmithKline
Merck & Co., Inc.
Schering-Plough Research Institute**

INTRODUCTION

For nearly 100 years, the medical community has been aware of heredity's powerful role in human health and disease. Yet a wide chasm filled with scientific uncertainties has stood between that understanding of the principles of human genetics and medicine's ultimate aim of alleviating human suffering. A bridge has now been constructed. Equipped with our newfound knowledge of the human genome - the Human Genome Project has laid the foundation for a genomics revolution that will change the face of medicine, of health and society, and other scientific applications in the 21st century.

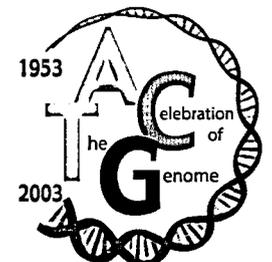
This public symposium, "Bringing the Genome to You," is designed to highlight the many ways in which the Human Genome Project will touch our lives. At the same time, it is a celebration of the remarkable progress in our understanding of the human genome and, thus, of ourselves. The symposium will provide a unique opportunity to hear from some of the world's leading scientific minds about the Human Genome Project, the new discoveries that lie just ahead, and the future developments in research and clinical practice that hold promise of even greater progress in the decades ahead.



Francis S. Collins, M.D., Ph.D.
Director
National Human Genome Research Institute
National Institutes of Health
Department of Health and Human Services



Aristides Patrinos, Ph.D.
Associate Director of Science
for Biological and Environmental Research
Department of Energy



AGENDA

Baird Auditorium
National Museum of Natural History
Smithsonian Institution
April 15, 2003

9:00 - 9:10 am
Introduction and Welcome
Cristián Samper, Ph.D.
National Museum of Natural History

Francis S. Collins, M.D., Ph.D.
National Human Genome Research Institute

Tommy Thompson
Department of Health and Human Services

9:10 - 9:20 am
Opening Remarks
James Watson, Ph.D.
Cold Spring Harbor Laboratories

9:20 - 9:25 am
Opening Remarks (Recorded)
Sir Francis Crick, Ph.D.
Salk Institute for Biological Studies

9:25 - 9:45 am
The Human Genome Project
Eric Lander, Ph.D.
Whitehead Institute Center for Genomic Research

9:45 - 10:05 am
Human Genome Project to Medicine
Wylie Burke, M.D., Ph.D.
University of Washington

10:05 - 10:25 am
The Media's View of the Genome
Robert Krulwich
ABC News

10:25 - 10:45 am
Break

10:45 am - 12:15 pm
Panel
Human Genome Project to Society
Robert Krulwich, Moderator
ABC News

Genetic Policy
Hon. Louise Slaughter
New York - D - 28th

Ethical Considerations
Thomas Murray, Ph.D.
Hastings Center

Consumer Interests
Kay Redfield Jamison, Ph.D.
Johns Hopkins University

Health Disparities
Harold Freeman, M.D.
National Cancer Institute

Disabilities
Paul Miller, J.D.
Equal Employment Opportunity Commission

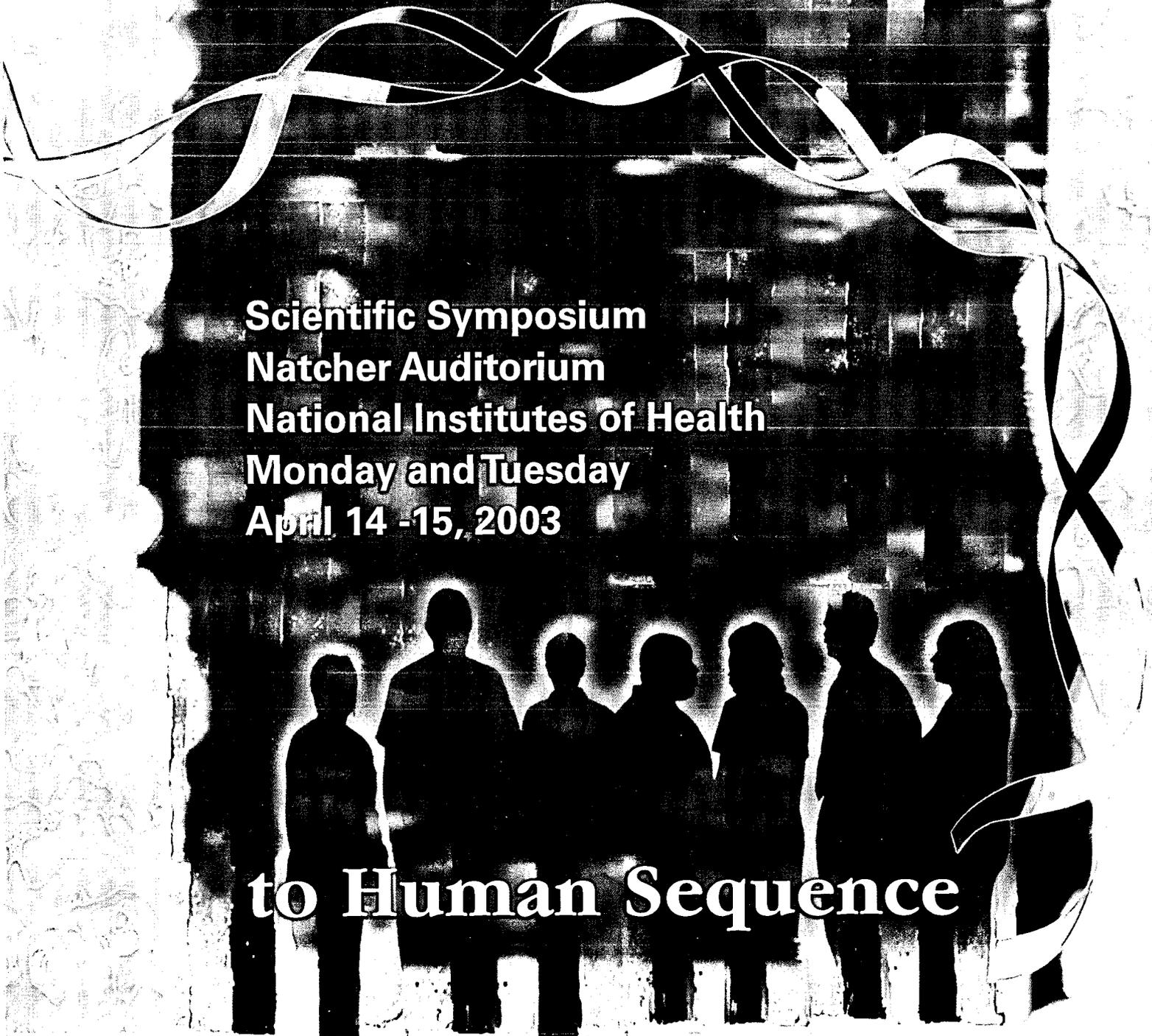
Historical Issues
Vanessa Gamble, M.D., Ph.D.
Johns Hopkins University

12:15 - 12:30 pm
A Perspective from the Department of Energy
Aristides Patrinos, Ph.D.
Department of Energy

12:30 - 1:00 pm
Human Genome Project and the Future
Francis S. Collins, M.D., Ph.D.
National Human Genome Research Institute



From Double Helix

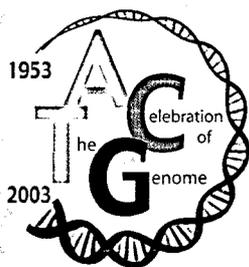


**Scientific Symposium
Natcher Auditorium
National Institutes of Health
Monday and Tuesday
April 14 -15, 2003**



to Human Sequence

- and Beyond



INTRODUCTION

FROM DOUBLE HELIX TO HUMAN SEQUENCE - AND BEYOND

In ancient times, Aristotle proposed the existence of some causal force that determines what makes an acorn develop into an oak tree. In modern times, scientists have begun to discern some of the fascinating steps that describe our own path from zygote to adult. The guiding instruction set behind our development, and the development of all living things, is DNA. The Human Genome Project set out to sequence the DNA of humans – to further the discovery of what helps make us who we are.

Today, April 14, 2003, an international consortium led by the National Human Genome Research Institute (NHGRI) of the National Institutes of Health in the Department of Health and Human Services and the Office of Science in the Department of Energy (DOE) announce the successful completion of all of the original goals of the Human Genome Project. The creative and collaborative efforts of researchers in China, France, Germany, Great Britain, Japan, and the United States have achieved these goals more than two years ahead of original schedule – and under budget. The project, begun in 1990, has already led to major innovations in biotechnology, and through its Ethical, Legal, and Social Implications program has established a new paradigm for exploring the social consequences of scientific discovery.

The accomplishment of sequencing our genome is the beginning of a new age of science. Numerous advances in medical research and practice have already begun to sprout from the seeds of the Human Genome Project.

The U.S. Congress has declared April 2003 as “Genome Month” and April 25th, the 50th anniversary of James Watson and Francis Crick’s landmark publication of the description of the structure of DNA, as “DNA Day.” It is to honor these two events that the NHGRI and the DOE have organized this scientific symposium, as well as a symposium for the public, numerous educational activities, and museum exhibits across the country. In addition, NHGRI unveils this month its bold, new vision for the future of genomics research.

This scientific symposium, “From Double Helix to Human Sequence – and Beyond,” is designed to provide a unique view into the beginnings, workings, future applications, and social issues of the Human Genome Project. It will give you an unparalleled opportunity to hear from some of the world’s leading experts on all of these topics, and will provide us with a glimpse of the many implications of the Human Genome Project for humankind. Welcome to the genome era.

Francis S. Collins, M.D., Ph.D.
Director
National Human Genome Research Institute
National Institutes of Health
Department of Health and Human Services

Aristides Patrinos, Ph.D.
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JAMES D. WATSON, PH.D.

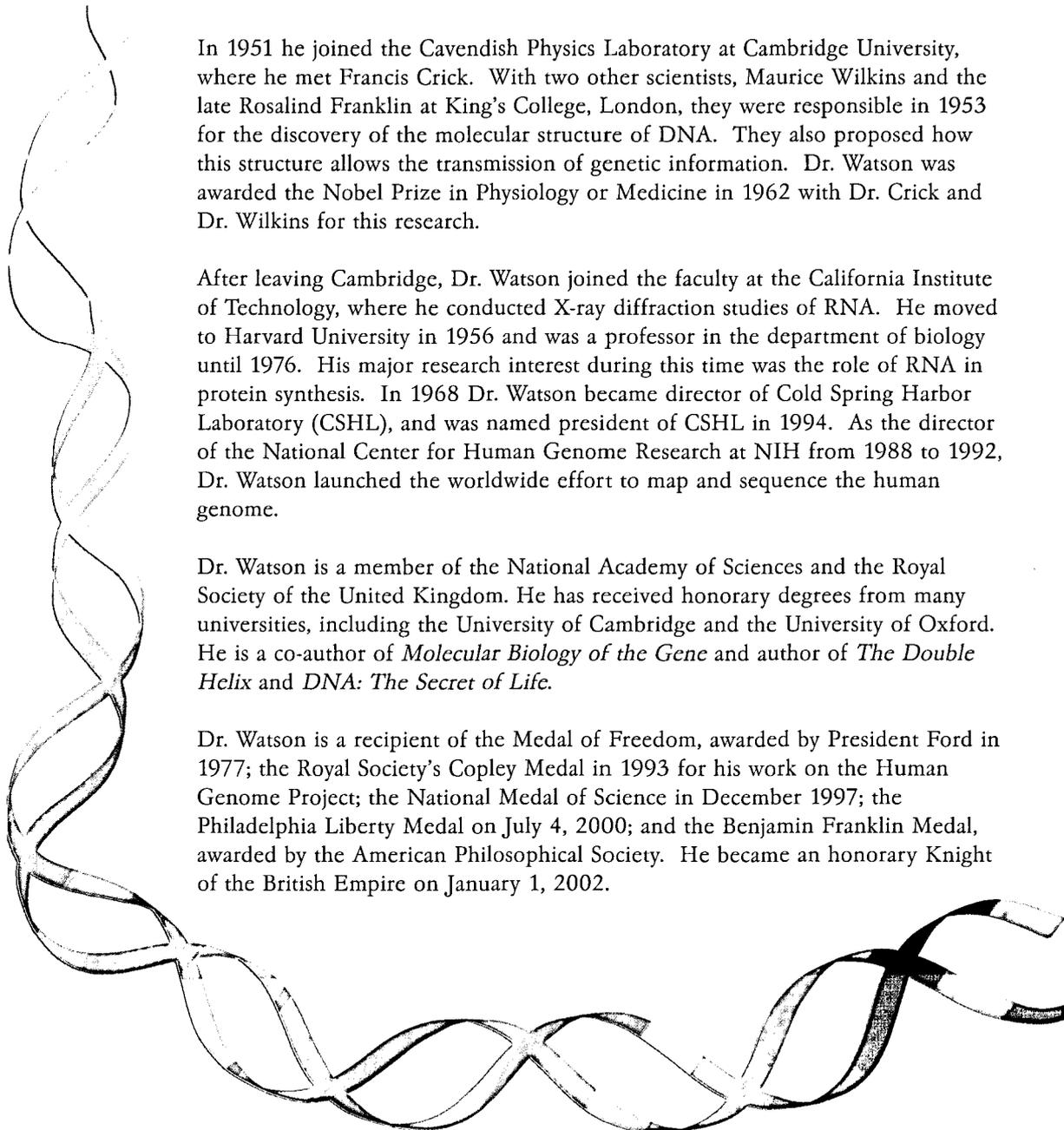
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FRANCIS CRICK, O.M., F.R.S., PH.D.

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Scientific Symposium
FROM DOUBLE HELIX TO HUMAN SEQUENCE - AND BEYOND

Natcher Auditorium, National Institutes of Health
Monday and Tuesday, April 14-15, 2003

Monday, April 14

AGENDA

- 8:30 a.m. Welcome **Elias Zerhouni**
National Institutes of Health
- 8:40 a.m. Opening Remarks **Francis Collins**
National Human Genome Research Institute, NIH
Aristides Patrinos
*Office of Biological and Environmental
Research, DOE*
- 8:50 a.m. Reflections on the 50th Anniversary **James Watson**
Cold Spring Harbor Laboratory
Francis Crick (Recorded)
Salk Institute for Biological Studies

FIRST SESSION: DNA AT 50 YEARS

Session Chair: **Herbert Boyer**, *University of California at San Francisco*

- 9:15 a.m. The film *Deciphering Nature's Alphabet: A Conversation - How Does DNA Work?*
- 9:25 a.m. Deciphering the Genetic Code **Marshall Nirenberg**
National Heart, Lung, and Blood Institute, NIH
- 9:45 a.m. The Road from the Double Helix to DNA Cloning **Stanley Cohen**
Stanford University

10:05 a.m. **BREAK**

Session Chair: **Edward Rubin**, *Lawrence Berkeley National Laboratory and Joint Genome Institute, DOE*

- 10:30 a.m. The film *Deciphering Nature's Alphabet: A Conversation - Manipulating DNA*
- 10:40 a.m. Decoding the Information in DNA **Phillip Sharp**
Massachusetts Institute of Technology
- 11:00 a.m. The film *Deciphering Nature's Alphabet: A Conversation - Developing Genetic Tools*
- 11:10 a.m. Ideological Consequences of the Human Genome Project **Horace Freeland Judson**
George Washington University
- 11:30 a.m. **LUNCH**



SECOND SESSION: THE HUMAN GENOME PROJECT

Session Chair: **James Wyngaarden**, *Duke University*

12:30 p.m. The film *Deciphering Nature's Alphabet: A Conversation - Imagining the Genome*

12:40 p.m. History of the Project:

Beginnings

Charles DeLisi
Boston University

1987 - 1990

Bruce Alberts
National Academy of Sciences

Getting the Job Done

Maynard Olson
University of Washington

Looking Beyond the Lab:
The Ethical, Legal, and Social
Implications Program

Eric Juengst
Case Western Reserve University

1:40 p.m. Beyond the Genome

Eric Lander
Whitehead Institute for Biomedical Research, MIT

2:05 p.m. **BREAK**

Session Chair: **Richard Gibbs**, *Baylor College of Medicine*

2:25 p.m. Introduction to the Watson Lecture

Kay Redfield Jamison
Johns Hopkins University
Chair, The Genome Action Coalition

2:30 p.m. **WATSON LECTURE**
Biology in the Era of
Complete Genomes

Shirley Tilghman
Princeton University

3:00 p.m. The film *Deciphering Nature's Alphabet: A Conversation - The Impact of the Human Genome Project*

3:10 p.m. HGP: Beyond the Human Sequence

The Mouse Genome:
A Reflection on the
Human Genome

Robert Waterston
University of Washington

New Frontiers in
Comparative Genomics

Eric Green
National Human Genome Research Institute, NIH

The Genome's Life Stories

Patrick Brown
Stanford University

Computational Genomics:
Sequence, Function,
and Evolution

David Haussler
University of California, Santa Cruz

Human Sequence Variation

David Bentley
The Wellcome Trust Sanger Institute

4:30 p.m.	The Road Ahead	Aristides Patrinos <i>Office of Biological and Environmental Research, DOE</i>
4:40 p.m.	A Vision for Genomics Research	Francis Collins <i>National Human Genome Research Institute, NIH</i>
5:00 p.m.	ADJOURN	



TUESDAY, APRIL 15

THIRD SESSION: IMPLICATIONS OF GENOMICS FOR HUMAN DISEASE

Session Chair: **Caroline A. Kovac**, *IBM Life Sciences*

8:30 a.m.	From Genome to Successful Treatment in Leukemia	Janet Rowley <i>University of Chicago</i>
	Genetic and Genomic Insights into Cardiovascular Disease	Richard Lifton <i>Yale University School of Medicine</i>
	Paradigms for the Genetic Component of Diabetes	Nancy Cox <i>University of Chicago</i>
	Gene Identification for Infectious Disease Resistance: The First 50 Years	Adrian Hill <i>The Wellcome Trust Centre for Human Genetics</i>
	Genetics of Asthma: Role of Nonlinear Gene-Environment Interactions	Fernando Martinez <i>University of Arizona</i>

9:45 a.m. Questions and Discussion

10:10 a.m. **BREAK**

Session Chair: **Michael Gottesman**, *National Institutes of Health*

10:30 a.m.	Genetics of Speech, Language, and Reading Disorders	Anthony Monaco <i>The Wellcome Trust Centre for Human Genetics</i>
	Hereditary Hearing Disorders in the Genomics Era	Thomas Friedman <i>National Institute on Deafness and Other Communication Disorders, NIH</i>
	Impact of the Human Genome Project on Hereditary Blindness, Simple and Complex	Val Sheffield <i>University of Iowa</i>
	Genetic Analysis Reveals Unexpected Connections Between Neurodegenerative Diseases	John Hardy <i>National Institute on Aging, NIH</i>

Genomic Views of Psychiatric Illness **Aravinda Chakravarti**
Johns Hopkins University School of Medicine

11:45 a.m. Questions and Discussion

12:10 p.m. LUNCH



FOURTH SESSION: IMPLICATIONS OF GENOMICS FOR HEALTHCARE

Session Chair: **Raynard Kington**, *National Institutes of Health*

1:30 p.m. Genomic Healthcare **Wylie Burke**
University of Washington

Genes, Genomes, and Drugs **Peter Goodfellow**
GlaxoSmithKline Pharmaceuticals

2:20 p.m. Questions and Discussion

2:40 p.m. BREAK



FIFTH SESSION: IMPLICATIONS OF GENOMICS FOR SOCIETY

Session Chair: **Ellen Wright Clayton**, *Vanderbilt University*

3:00 p.m. Race, Science, and Society **Harold Freeman**
National Cancer Institute, NIH

Intellectual Property:
A Boon or a Barrier to Genomics? **Maria Freire**
*The Global Alliance for Tuberculosis
Drug Development*

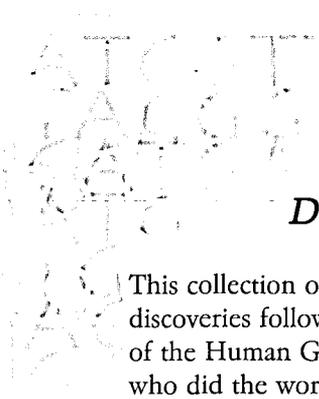
The Genetic Revolution
and Its Impact in the Workplace **Paul Miller**
U.S. Equal Employment Opportunity Commission

Forensic DNA Testing and
Human Identification **Robert Shaler**
*Office of the Chief Medical Examiner,
New York City*

4:00 p.m. Questions and Discussion

4:30 p.m. Genomics and Global Health **David Weatherall**
University of Oxford

5:00 p.m. ADJOURN



Deciphering Nature's Alphabet: A Conversation

This collection of short documentary films provides a unique perspective on the key genetic discoveries following the discovery of the double helix in 1953 and leading to the completion of the Human Genome Project in 2003 — and beyond. The conversation is with the people who did the work, as well as their contemporaries.

The first film, “How Does DNA Work?” (featuring Drs. Sydney Brenner, Matthew Meselson and Maxine Singer) portrays the key biological discoveries that immediately arose from the Watson-Crick discovery of the double helix structure of DNA, including genetic replication, messenger RNA, transfer RNA, and the genetic code.

The second film, “Manipulating DNA,” (featuring Drs. David Baltimore, Herbert Boyer, Jonathan Beckwith) describes the first steps toward using the DNA molecule itself for research, including isolating the first gene, discovering reverse transcriptase, developing techniques for genetic engineering, and the controversies surrounding early genetic research.

The third film, “Developing Genetic Tools,” (featuring Drs. Walter Gilbert, David Botstein and Nancy Wexler) tells of the development of technologies for sequencing DNA and mapping genomes, which led to the mapping of the first human disease gene, Huntington disease.

The fourth film, “Imagining the Genome,” (featuring Drs. James Watson, Leroy Hood, Robert Sinshimer, Senator Pete Domenici, and Ms. Patricia King) depicts the story of the Human Genome Project, including how the idea of the project emerged, the manner of its launching, its early proponents, initial obstacles, and the creation of the Ethical, Legal, and Social Implications Program.

The fifth film, “The Impact of the Human Genome Project,” (featuring Drs. Gerald Rubin, J. Craig Venter, Nancy Wexler, and Senator Pete Domenici) peers into the future and describes how the results of the Human Genome Project will change the future of research and medical practice. This view includes the development of new treatments, personalized and preventive medicine, and new scientific understandings of the way in which the genome evolved, and how it encodes the biological properties of our species.

Deciphering Nature's Alphabet: A Conversation was produced for the National Human Genome Research Institute of the National Institutes of Health in the Department of Health and Human Services by State of the Art, Inc., a Washington, D.C. documentary production company.



BIOGRAPHICAL SKETCHES



ELIAS ZERHOUNI, M.D.

Dr. Zerhouni is the director of the National Institutes of Health. He was most recently executive vice dean of the Johns Hopkins University School of Medicine, chair of the Russell H. Morgan Department of Radiology and Radiological Sciences, Martin Donner Professor of Radiology, and professor of biomedical engineering. His past research includes the development of new technology, including computer techniques to determine whether nodules found on the lung are benign or malignant, a new way to assess heart function with magnetic resonance imaging, and a method of high-resolution CT for both anatomic and physiologic studies of the lung. Dr. Zerhouni received his M.D. from the University of Algiers School of Medicine in 1975 and completed his residency in diagnostic radiology at Johns Hopkins in 1978 as chief resident.



FRANCIS S. COLLINS, M.D., PH.D.

Dr. Collins is director of the National Human Genome Research Institute (NHGRI). He oversees the Human Genome Project, which finished the human genome sequence this week. Dr. Collins also leads the NHGRI's effort to use genomic knowledge to improve human health and to benefit society. His lab is currently searching for genes that contribute to type II diabetes. His previous research led to the identification of genes responsible for cystic fibrosis, neurofibromatosis, and Huntington disease. Dr. Collins received his B.S. from the University of Virginia, his Ph.D. in physical chemistry from Yale University, and his M.D. from the University of North Carolina. The recipient of numerous scientific awards, he is a member of the National Academy of Sciences and the Institute of Medicine.



ARISTIDES PATRINOS, PH.D.

Dr. Patrinos is associate director for biological and environmental research in the Department of Energy's (DOE) Office of Science, where he oversees research in genomics, structural biology, nuclear medicine, global climate change, and environmental remediation. He is the director of DOE's component of the Human Genome Project. Dr. Patrinos has a degree in engineering from the National Technical University of Athens, Greece, and received his Ph.D. in mechanical engineering and astronautical sciences from Northwestern University.



HERBERT W. BOYER, PH.D.

Dr. Boyer is a co-founder of Genentech, Inc. He was a professor of biochemistry and biophysics at the University of California at San Francisco, where he directed the graduate program in genetics. He is the recipient of the Lemelson-MIT Prize and the Swiss Helmut Horten Research Award and was elected to the National Inventors Hall of Fame in 2001. Dr. Boyer received his master's and doctoral degrees from the University of Pittsburgh.



MARSHALL W. NIRENBERG, PH.D.

Dr. Nirenberg received his Ph.D. in biochemistry from the University of Michigan and trained as a postdoctoral fellow with Dewitt Stetten, Jr. at the National Institutes of Health. He and his colleagues deciphered the genetic code between 1961 and 1966. In 1968 he won the Nobel Prize in Medicine or Physiology with Har Gobind Khorana and Robert W. Holley. Dr. Nirenberg is chief of the laboratory of biochemical genetics at the National Heart, Lung, and Blood Institute.



STANLEY N. COHEN, M.D.

Dr. Cohen is the Kwoh-Ting Li Professor of Genetics and a professor of medicine at Stanford University. In 1973, he and Dr. Herbert Boyer discovered methods for cloning DNA. They are named as inventors on the patents underlying the field of genetic engineering, also known as recombinant DNA. Dr. Cohen is a recipient of the National Medal of Science, the National Medal of Technology and the Lasker Award for Basic Research.



EDWARD RUBIN, M.D., PH.D.

Dr. Rubin is director of the Department of Energy's Joint Genome Institute and head of the Genome Sciences Division at the Lawrence Berkeley National Laboratory. His research focuses on the development of computational and biological approaches to the analysis of DNA sequence data. He received his B.A. in physics from the University of California, San Diego, his M.D. from the University of Rochester Medical Center, and his Ph.D. in biophysics from the University of Rochester.



PHILLIP A. SHARP, PH.D.

Dr. Sharp is professor and director of the McGovern Institute for Brain Research at the Massachusetts Institute for Technology. He discovered RNA splicing in 1977, which provided one of the first indications of “discontinuous genes” in mammalian cells. In 1993 he won the Nobel Prize in Physiology or Medicine for this work. Dr. Sharp is a member of the National Academy of Sciences. He received his Ph.D. in chemistry from the University of Illinois at Urbana-Champaign in 1969.



HORACE FREELAND JUDSON

Mr. Judson is director of the Center for History of Recent Science and research professor of history at the George Washington University. He writes on major developments in biology and on the conduct of scientific research. He is the author of *The Eighth Day of Creation*, recognized as the definitive history of molecular biology through 1970. Mr. Judson is presently completing a book on fraud and the governance of science.



JAMES B. WYNGAARDEN, M.D.

Dr. Wyngaarden was the director of the National Institutes of Health from 1982 to 1989. He was chairman of the department of medicine at Duke University School of Medicine from 1967 to 1982. He is a past director of the Human Genome Organization and was foreign secretary of the National Academy of Sciences from 1990 to 1994. Dr. Wyngaarden received his M.D. from the University of Michigan.



CHARLES DELISI, PH.D.

Dr. DeLisi is the Arthur GB Metcalf Professor of Science and Engineering at Boston University, where he served as dean of engineering from 1990 to 2000. He has authored or co-authored more than 200 research papers in chemistry, mathematics, immunology, and genomics, and is founder and president of Pharmadyne Inc., a biotech start-up focused on AIDS and other viral diseases. In January 2000, he was awarded the Presidential Citizens Medal by President Clinton for his role in initiating the Human Genome Project.



BRUCE ALBERTS, PH.D.

Dr. Alberts is president of the National Academy of Sciences. His past research includes extensive study of the protein complexes that allow chromosomes to be replicated. Dr. Alberts received his Ph.D. from Harvard University in 1965. He was formerly a member of the faculty at Princeton University and chairman of the department of biochemistry and biophysics at the University of California, San Francisco. He is an author of the textbook, *The Molecular Biology of the Cell*.



MAYNARD OLSON, PH.D.

Dr. Olson graduated from the California Institute of Technology and received his Ph.D. in inorganic chemistry from Stanford University. He later changed his research emphasis to genetics and has since participated in the development of a wide range of techniques for large-scale genomic analysis. He is a professor of medicine and genomic sciences at the University of Washington and director of the University of Washington Genome Center.



ERIC JUENGST, PH.D.

Dr. Juengst is an associate professor of bioethics at Case Western Reserve University. He serves on the National Advisory Board for the National Human Genome Research Institute (NHGRI). Dr. Juengst received his Ph.D. in Philosophy from Georgetown University. He has taught bioethics as a faculty member of the medical schools at the University of California, San Francisco and Penn State University. He was the first chief of NHGRI's Ethical, Legal, and Social Implications program.



ERIC LANDER, PH.D.

Dr. Lander is founder and director of the Whitehead Institute Center for Genome Research and a professor of biology at the Massachusetts Institute of Technology. He is one of the principal leaders of the Human Genome Project. Dr. Lander received his B.A. in mathematics from Princeton University and his Ph.D. in mathematics from Oxford University. He is a member of the National Academy of Sciences, the Institute of Medicine, and the American Academy of Arts and Sciences.



RICHARD GIBBS, PH.D.

Dr. Gibbs received his Ph.D. from the University of Melbourne, Australia. He is the Wofford Cain Professor of Molecular and Human Genetics, and director of the Baylor College of Medicine – Human Genome Sequencing Center (BCM-HGSC). The BCM-HGSC has completed approximately ten percent of the Human Genome Project sequence, as well as one-third of the fruit fly sequence and drafts of the rat, *Drosophila pseudoobscura*, and honeybee genomes. The center has also generated about one third of all known human and mouse, full-length cDNA sequences.



KAY REDFIELD JAMISON, PH.D.

Dr. Jamison is professor of psychiatry at the Johns Hopkins School of Medicine. She is the author of *An Unquiet Mind*, *Night Falls Fast*, and *Touched With Fire*, and co-author of the standard medical text on manic-depressive illness. She is chair of The Genome Action Coalition (TGAC) and was a member of the first National Advisory Council for the National Center for Human Genome Research. Dr. Jamison was awarded a MacArthur Fellowship in 2001.

THE JAMES D. WATSON LECTURE

The Lecture is sponsored annually by The Genome Action Coalition (TGAC), which unites more than 130 patient advocacy and professional organizations, corporations, and others in support of public and private genomic and genetic research. The organizers of this symposium and TGAC thought it appropriate to include the Watson Lecture within this historic symposium, honoring two projects in which Dr. Watson played key roles, the description of DNA 50 years ago and the finishing of the Human Genome Project.

This year's Watson Lecturer, Dr. Shirley Tilghman, President of Princeton University, was selected based upon her internationally recognized scholarship in molecular biology and leadership in academia.



SHIRLEY M. TILGHMAN, PH.D.

Dr. Tilghman is president of Princeton University. She is also the Howard A. Prior Professor of the Life Sciences at Princeton and an investigator at the Howard Hughes Medical Institute. Her present research includes studies on genomic imprinting. Dr. Tilghman proposed the first model to explain the mechanism of parent-specific silencing of genes. Dr. Tilghman received her Honors B.Sc. in chemistry from Queen's University in Kingston, Ontario, and her Ph.D. in biochemistry from Temple University.



ROBERT H. WATERSTON, M.D., PH.D.

Dr. Waterston is Gates Professor and chair of the Department of Genome Sciences at the University of Washington. He helped to establish the nematode *Caenorhabditis elegans* as a powerful experimental organism. More recently, he has been a leader in the genome mapping and sequencing of humans and mice. Dr. Waterston is a member of the National Academy of Sciences and the Institute of Medicine. He is a recipient of the Beadle Medal, the Gardner Award, and the Sloan Award.



ERIC D. GREEN, M.D., PH.D.

Dr. Green received his M.D. and Ph.D. in 1987 from Washington University. Following a pathology residency and postdoctoral training, he became an assistant professor at Washington University in 1992. In 1994, he joined the Division of Intramural Research at the National Human Genome Research Institute (NHGRI). In addition to serving as chief of the Genome Technology Branch and director of the NIH Intramural Sequencing Center, Dr. Green was appointed as scientific director of NHGRI in 2002.



PATRICK O. BROWN, M.D., PH.D.

Dr. Brown is professor of biochemistry at Stanford University. His research uses DNA microarrays and other genomic approaches to explore a wide range of fundamental questions in gene regulation, cell biology, physiology, development and medicine. He received his B.A., M.D. and Ph.D. from the University of Chicago. He completed a pediatrics residency at Children's Memorial Hospital and conducted his post-doctoral studies at the University of California, San Francisco.



DAVID HAUSSLER, PH.D.

Dr. Haussler is the director of the Center for Biomolecular Science and Engineering at the University of California, Santa Cruz and holds the University of California Presidential Chair in Computer Science at the Santa Cruz campus. He is an investigator for the Howard Hughes Medical Institute and serves as a scientific co-director of California's tri-campus Institute for Quantitative Biomedical Research. He received his Ph.D. in computer science from the University of Colorado at Boulder.



DAVID BENTLEY, D.PHIL.

Dr. Bentley is head of human genetics at The Wellcome Trust Sanger Institute, United Kingdom. His research includes the construction of physical and gene maps of human chromosomes, the annotation and identification of genes associated with genetic disease, and the study of human sequence variation and patterns of common haplotypes in the genome. Dr. Bentley received his D. Phil. from the University of Oxford.



CAROLINE A. KOVAC, PH.D.

Dr. Kovac is the general manager of IBM Life Sciences, which develops information technology solutions for the life sciences market, including the biotechnology, genomic, and pharmaceutical industries. Her prior appointments at IBM include vice president of technical strategy and division operations and head of research efforts in computational biology. Dr. Kovac is a member of the Women in Technology International Hall of Fame. She received her Ph.D. in chemistry from the University of Southern California.



JANET ROWLEY, M.D.

Dr. Rowley received her undergraduate and medical degrees from the University of Chicago and joined the faculty there in 1962, becoming the Blum-Riese Distinguished Service Professor of Medicine in 1984. Using chromosome-banding techniques, she showed that the Philadelphia chromosome in chronic myeloid leukemia was the result of a translocation between chromosomes 9 and 22. This provided the basis for cloning the involved genes and development of the very successful Imatinib therapy. Dr. Rowley received the Lasker Award for Medical Research in 1998.



RICHARD P. LIFTON, M.D., PH.D.

Dr. Lifton is an investigator of the Howard Hughes Medical Institute and chair of the Department of Genetics at Yale University. His laboratory has identified genes and pathways underlying hypertension, stroke, osteoporosis, and electrolyte disorders, providing new insight into normal and disease physiology, as well as targets for the development of novel therapeutic approaches to these diseases. He is a member of the National Academy of Sciences and the Institute of Medicine.



NANCY COX, PH.D.

Dr. Cox is a quantitative human geneticist and associate professor of human genetics and medicine at the University of Chicago. Her research program focuses on the development and extension of genetic analysis methods for application to complex phenotypes. She has a long-standing interest in the genetics of diabetes, including type I diabetes, type II diabetes, and maturity onset diabetes of the young (MODY). Dr. Cox received her Ph.D. in human genetics from Yale University.



ADRIAN V.S. HILL, PH.D.

Dr. Hill is professor of human genetics at the Wellcome Trust Centre for Human Genetics at Oxford University. He has studied genetic variation in susceptibility to several infectious diseases in tropical countries. His work on HLA variation and malaria susceptibility led to the design of novel candidate vaccines for this disease. His most recent genome-wide linkage studies of tuberculosis, leprosy, and hepatitis resulted in the identification of novel susceptibility loci.



FERNANDO D. MARTINEZ, M.D.

Dr. Martinez is director of the Arizona Respiratory Center and Swift-McNear Professor of Pediatrics at the University of Arizona. His research interests include the natural history of childhood asthma, the genetic epidemiology of asthma and related conditions, and the early development of the immune system as a risk factor for the development of asthma. He is a principal investigator of Innate Immunity, one of the National Heart, Lung, and Blood Institute's Programs for Genomic Applications.



MICHAEL M. GOTTESMAN, M.D.

Dr. Gottesman is deputy director for intramural research at the National Institutes of Health (NIH) and chief of the Laboratory of Cell Biology at the National Cancer Institute. He served as the acting director of the National Center for Human Genome Research from 1992 to 1993. Dr. Gottesman received his M.D. from Harvard University Medical School and completed his postdoctoral training in molecular genetics at the NIH, where he worked with Martin Gellert.



ANTHONY P. MONACO, M.D., PH.D.

Professor Monaco received his M.D. and Ph.D. from Harvard Medical School. In 1995, he was awarded a Wellcome Trust Principal Research Fellowship and joined the Wellcome Trust Centre for Human Genetics at Oxford University, where he works on the genetic basis of neurological and psychiatric disorders, including autism and developmental language and reading disorders. In 1998, he was appointed as director of the Wellcome Trust Centre for Human Genetics.



THOMAS B. FRIEDMAN, PH.D.

Dr. Friedman is Chief of the Laboratory of Molecular Genetics at the National Institute on Deafness and Other Communication Disorders at the National Institutes of Health. He received his B.S. in 1966 and his Ph.D. in 1971 from the University of Michigan, where he worked with Tahir M. Rizki. He began his research on hereditary deafness at Michigan State University in 1986, with his colleague and friend, the late James H. Asher, Jr.



VAL SHEFFIELD, M.D., PH.D.

Dr. Sheffield is professor of pediatrics and director of the Division of Medical Genetics at the University of Iowa College of Medicine. He is also an associate investigator of the Howard Hughes Medical Institute. Dr. Sheffield received his Ph.D. in developmental biology and his M.D., with honors, from the University of Chicago. His post-graduate training in pediatrics and medical genetics took place at the University of California, San Francisco.



JOHN HARDY, PH.D.

Dr. Hardy is chief of the Laboratory of Neurogenetics at the National Institute on Aging at the National Institutes of Health. He received his Ph.D. in neurochemistry at Imperial College, London, in 1979. He previously held positions at Imperial College, the University of South Florida and the Mayo Clinic, where he was the founding chair of the department of neuroscience. Dr. Hardy has won numerous prizes for his work dissecting the genetic causes of the dementias.



ARAVINDA CHAKRAVARTI, PH.D.

Dr. Chakravarti is a professor and the director of the McKusick-Nathans Institute of Genetic Medicine at Johns Hopkins University School of Medicine. His research is aimed at understanding the molecular basis of common genetic disorders using contemporary genomic tools. He is an expert on statistical genetics and studies predisposing genetic factors in such common and complex human diseases as diabetes, heart disease, and mental illness.



RAYNARD S. KINGTON, M.D., PH.D.

Dr. Kington serves as deputy director of the National Institutes of Health. He received his M.D. from the University of Michigan. After completing his residency in internal medicine, he was appointed a Robert Wood Johnson clinical scholar at the University of Pennsylvania. While there he completed a Ph.D. with a concentration in health policy and economics at the Wharton School. His research focuses on the role of social factors as determinants of health.



WYLIE BURKE, M.D., PH.D.

Dr. Burke is chair of the Department of Medical History and Ethics and adjunct professor of medicine and epidemiology at the University of Washington. Her research addresses the ethical and health policy implications of genetic information. She is currently a member of the National Advisory Council for Human Genome Research. Dr. Burke received a Ph.D. in genetics and an M.D. from the University of Washington, where she also completed a residency in internal medicine.



PETER GOODFELLOW, PH.D.

Dr. Goodfellow is senior vice president of Discovery Research at GlaxoSmithKline. Previously, he worked at the Imperial Cancer Research Fund and Cambridge University in the United Kingdom. His academic interests were in genome mapping technologies and the genetics of sex determination. Dr. Goodfellow's current passion is trying to make new therapeutics by exploiting information from the human genome.



ELLEN WRIGHT CLAYTON, M.D., J.D.

Dr. Clayton is the Rosalind E. Franklin Professor of Genetics and Health Policy, a professor of pediatrics, and a professor of law at Vanderbilt University. She has been exploring the implications of genetics for 25 years. Dr. Clayton is a past member of the National Human Genome Research Institute's National Advisory Council, and its Ethical, Legal, and Social Implications Research Planning and Evaluation Group. She currently serves as a major advisor to the International Haplotype Map Project.



HAROLD P. FREEMAN, M.D.

Dr. Freeman is an associate director of the National Cancer Institute (NCI) and director of the NCI Center to Reduce Cancer Health Disparities. He serves as the director of surgery at North General Hospital in New York City and is clinical professor of surgery at Columbia University College of Physicians and Surgeons. A past president of the American Cancer Society, he is a leading authority on the relationship between race, poverty, and cancer.



MARIA C. FREIRE, PH.D.

Dr. Freire is the chief executive officer of the Global Alliance for Tuberculosis Drug Development, a not-for-profit international organization working towards the development of faster-acting and affordable anti-tuberculosis drugs. Prior to this position, Dr. Freire was the director of the Office of Technology Transfer at the National Institutes of Health for seven years. She received her Ph.D. in biophysics from the University of Virginia in 1981.



PAUL STEVEN MILLER, J.D.

Mr. Miller is a commissioner of the U.S. Equal Employment Opportunity Commission (EEOC). He participates with the other four commissioners in the development and approval of EEOC enforcement policies, authorization of litigation, and issuance of commissioners' charges of discrimination. Mr. Miller also served as a member of the interagency working group that drafted the Presidential Executive Order on Genetic Discrimination and Privacy. He received his Juris Doctor from the Harvard Law School.



ROBERT C. SHALER, PH.D.

Dr. Shaler is the director of forensic biology at the Office of the Chief Medical Examiner for the city of New York, the largest public forensic DNA laboratory in the United States. His laboratory is responsible for the DNA analysis of biological evidence resulting from rapes and homicides in the city. Dr. Shaler also manages the DNA testing used to identify the missing after the World Trade Center attacks on September 11, 2001.



DAVID WEATHERALL, M.D.

Professor Weatherall is Regius Professor of Medicine Emeritus at the University of Oxford. His main research has been in the genetic disorders of hemoglobin. In 1989, he founded the Institute of Molecular Medicine at Oxford, since renamed the Weatherall Institute. He is a Fellow of the Royal Society and a foreign associate of the National Academy of Sciences. In 2002, he was lead author of the World Health Organization's report, *Genomics and World Health*.



ACKNOWLEDGEMENTS

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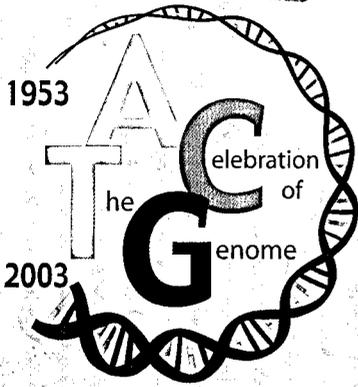
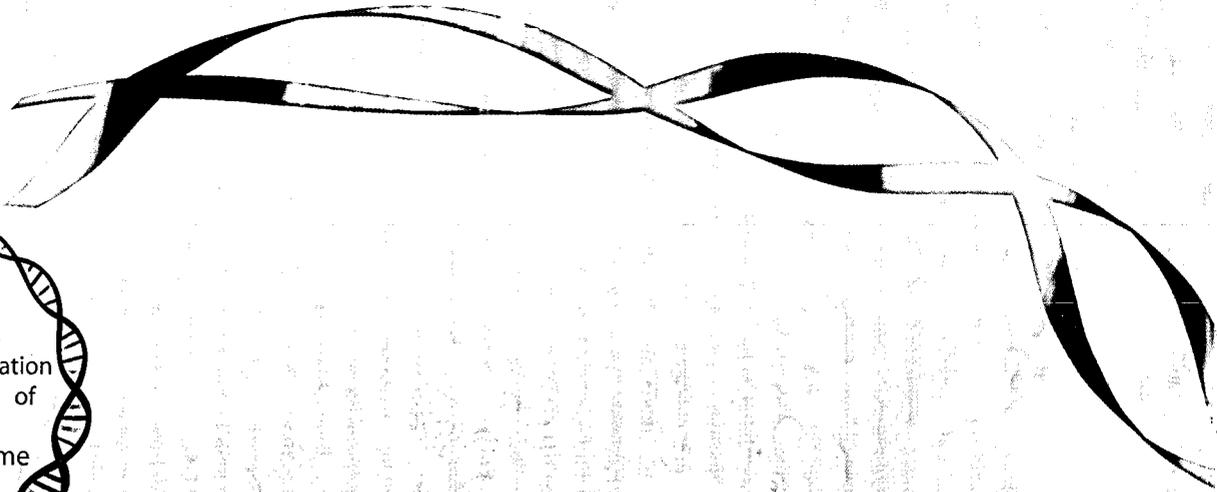
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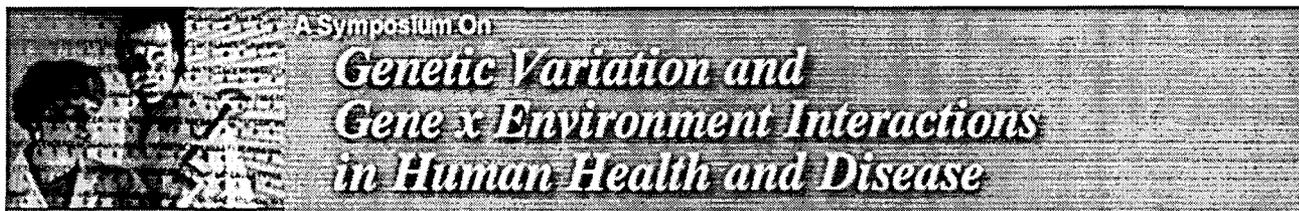
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Agenda

- 8:30-8:40** *Welcome and Introduction*
Samuel Wilson, NIEHS, NIH
- Session I** **CHAIR: Lisa Brooks**, NHGRI, NIH
- 8:40-9:10** *Patterns of Human Genetic Variation*
Lynn Jorde, University of Utah
- 9:10-9:40** *SNPing in the Human Genome*
Debbie Nickerson, University of Washington
- 9:40-10:10** *Influence of DNA Variation on Gene Expression*
Jeff Trent, Translational Genomics Research Institute
- 10:10-10:40** *Relating Variation to Phenotype*
Charles Rotimi, Howard University
- 10:40-10:50** **BREAK**
- Session II** **CHAIR: Samuel Wilson**, NIEHS, NIH
- 10:50-11:20** *Functional Genomics of Paraoxonase (PON1) Polymorphisms*
Clement Furlong, University of Washington
- 11:20-11:50** *Gene-Environment Interaction Related to Alcohol Use and Its Consequences*
David Crabb, Indiana University
- 11:50-12:20** *Gene-Environment Interactions in BRCA Related Breast Cancer*
Mary-Claire King, University of Washington

12:20- 12:50 *Gene-Environment Interactions in Human Leukemia*
Martyn Smith, University of California at Berkeley

12:50-1:30 **Audience Participation and Discussion**

Contact the Symposium Coordinator

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Symposium Administration (Restricted Directory)

A Celebration of the Genome
Fifty- Years of DNA: From Double Helix to Health
Information Sheet

Background:

April 2003 will witness three major events:

1. The essential completion of the sequencing of the human genome.
2. The 50th anniversary of James Watson and Francis Crick's Nobel Prize winning description of the DNA double helix.
3. The publication of a new plan for the future of genomic science.

To mark these achievements, the NHGRI, the NIH, HHS and the DOE are planning a month-long series of scientific, educational, cultural and celebratory events across the United States.

Detailed information located at www.genome.gov/About/April2003

Date Specific Events:

Two- Day Scientific Symposium

"From Double Helix to Human Sequence- and Beyond"

April 14-15, 2003- each day runs from 8:30 am to 5:00 pm

Natcher Conference Center, NIH

Bethesda, MD

Registration Site: <http://www.genome.gov/About/April2003/Scientific/>

Registration opened on Feb. 18 at 8:30 am.

Symposium will be web cast and available via satellite, contact: Maggie Bartlett

Press Conference

April 14, 2003- 11:30 to 12:30 pm

Natcher Conference Center, NIH

Bethesda, MD

Only open to media and select sequencing center representatives.

Half-Day Public Symposium

"Bringing the Genome to You"

April 15, 2003- 9:00 am to 1:00 pm

Baird Auditorium- National Museum of Natural History

Washington, DC

Registration Site: <http://www.genome.gov/About/April2003/Public/>

Registration opened on Feb. 18 at 8:30 am.

Symposium will be web cast and available via satellite, contact: Maggie Bartlett

Scholarships for travel are available, contact: Laura Rodriguez

DNA Day

April 25, 2003

Teachers and students throughout the country are encouraged to join in the celebration by using the educational tools on our website: www.genome.gov/About/April2003/DNAday

Contact: Susan Vasquez

Minority students and teachers will be nominated through our strategic partners and be brought in for the event, contact: Vence Bonham.

Invitation Only Events:

Reception (pending, depending upon availability of funding)

April 13, 2003

Location TBA

Attendance by invitation only- to include symposium speakers, vignette interviewees, sponsor representatives, and NHGRI staff.

Gala Dinner

April 14, 2003

Great Hall of the Library of Congress

Sponsored by the Foundation for the NIH

Attendance by invitation only- to include speakers, VIP's, Congressional Representatives, and sponsors.

Educational Taping Event

April 15, 2003

Atlantic Video or White House

Attendance by invitation only- to include high school students/teachers and a few NHGRI staff.

Mini Symposia hosted by other IC's:

Afternoon Scientific symposium

“Linking the Double Helix with Health: Genetics in Nursing Research”

April 13, 2002

Sponsored by NINR

Georgetown University

<http://www.nih.gov/ninr/news-info/geneventposter.pdf>

Morning Scientific Symposium

“Gene and Environment Interactions”

April 16, 2003

Sponsored by NIEHS

NIH Campus

<http://www-apps.niehs.nih.gov/odconfer/gxe/home.htm>

All-day Scientific Symposium
“Genes, Brain, Behavior: Before and Beyond Genomics”
April 16, 2003
Sponsored by NIMH and other NIH ICs
NIH Campus
<http://www.nimh.nih.gov/>

Month Long Activities:

Congressional Proclamation

Proclamation of April 2003 as “Human Genome Month” and April 25th, the 50th anniversary of the publication that first described the structure of DNA, as “DNA Day.”
Contact: Tim Leshan

International Statement

Statement from heads of state, honoring the essential completion of sequencing the human genome.
Contact: Tim Leshan

Museums

Activities at Science Museums across the country. NHGRI is working with the Association of Science and Technology Centers (ASTC) to award 30 museums with a DNA Museum Kit. The Museums have already been chosen and will be posted on our website.
Contact: Kris Wetterstrand

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50 YEARS OF DNA: FROM DOUBLE HELIX TO HEALTH

APRIL 2003

Sunday, April 13:

- An afternoon scientific symposium at Georgetown University, “**Linking the Double Helix with Health: Genetics in Nursing Research**,” sponsored in part by the National Institute of Nursing Research (for more information, see <http://www.nih.gov/ninr/news-info/geneventposter.pdf> or contact Mindy Tinkle at 402-7889 or at tinklem@mail.nih.gov).
- ***Tentative*** An evening **opening reception** for symposia speakers, leaders of the Human Genome Project, other leaders of genomics, special guests, and the NHGRI family.

Monday, April 14 and Tuesday, April 15:

- A two-day **scientific symposium** at the NIH’s Natcher Conference Center that will be web and satellite cast around the world. Speakers will describe the science and history of the Human Genome Project. In addition, the symposium will explore the future of science and medicine made possible by breakthroughs in genomic science, and will include the unveiling of a new plan for the future of genomics and of the NHGRI (see draft agenda). Free registration will become available in early February and will be made known to NHGRI staff when it occurs.

Monday, April 14:

- A **gala dinner** at the Great Hall of the Library of Congress, hosted by the Foundation for the NIH, for several hundred leaders of government, science, and industry, many of who played key roles in the Human Genome Project.

Tuesday, April 15:

- On the morning of the 15th, a half-day **public symposium** will be held at the Smithsonian’s National Museum of Natural History and will be web and satellite cast around the world. (see draft agenda). Free registration will become available in early February and will be made known to NHGRI staff when it occurs.
- On the afternoon of the 15th, an **education session** in the Washington, DC area. The session will include Drs. Watson and Collins, and will be moderated by Robert Krulwich. Selected teachers and students from the Washington, DC area and from around the nation will participate in the event, which will be edited for later use, including as part of “DNA Day” (see below). The First Lady has been invited to host this event at the White House.

Wednesday, April 16:

- At the NIH, a morning scientific symposium, “**Gene and Environment Interactions**,” sponsored by the National Institute of Environmental Health Sciences (see draft agenda; for more information, contact Sam Wilson at (919) 541-3267 or at wilson5@niehs.nih.gov).
- At the NIH, an all-day scientific symposium, “**Genes, Brain, Behavior: Before and Beyond Genomics**,” sponsored by the National Institute of Mental Health and other NIH ICs (see draft agenda; for more information, contact Steve Moldin at 443-9869 or at smoldin@mail.nih.gov).

Friday, April 25:

- A national “**DNA Day**,” on which high schools throughout the country celebrate the 50th anniversary of the description of the DNA double helix. Schools will utilize such tools as a videotape of the educational event on April 15th, the NHGRI multimedia education kit, and the NHGRI-American Society of Human Genetics mentors’ network. High schools will be encouraged to make this the culmination of a month-long focus on genetics, to involve numerous other activities.

In addition to these date-specific events, other activities include:

- 1) Congressional Proclamation of April 2003 as “**Human Genome Month**” and April 25th, the 50th anniversary of the publication that first described the structure of DNA, as “**DNA Day**.”
- 2) An **international statement** from heads of state, honoring the essential completion of sequencing the human genome.
- 3) **Activities at science museums** across the country. Items available to museums will include a program guide of genomics-related events, a training workshop for museum staff, a kit of materials and equipment, and advertising graphics to call attention to the events.
- 4) **Public outreach** through television, radio and print features on genetics and genomics.
- 5) A plan for bringing the April 2003 celebration of genomics to the **classroom** by inviting teachers and students to join in the recognition of these historic achievements through direct mailings and frequent communication. Lesson plans, challenging activities and curriculum supplements regarding the Human Genome Project, genomic science, and the basics of human genetics are being made available on-line.

DRAFT 1/21/03

Scientific Symposium: From Double Helix to Human Sequence - and Beyond
Natcher Auditorium, National Institutes of Health Monday and Tuesday, April 14-15, 2003
Monday, April 14, 2003

First Session: DNA at 50 years

8:30 a.m. Welcome Elias Zerhouni
8:40 a.m. Opening remarks Francis Collins/Ari Patrinos
8:50 a.m. Reflections on the 50th Anniversary James Watson
Francis Crick (recorded)

Moderator: Herb Boyer

9:15 a.m. Recorded vignettes I
9:25 a.m. Cracking the Genetic Code Marshall Nirenberg
9:45 a.m. DNA as a Reagent Stanley Cohen
10:05 a.m. Break

Moderator: Eddy Rubin

10:30 a.m. Recorded vignettes II
10:40 a.m. DNA as Information: The Central Dogma & Some Interesting Exceptions Phil Sharp
11:00 a.m. Recorded vignettes III
11:10 a.m. Reflections of a Molecular Biology Historian Horace Freeland Judson
11:30 p.m. Lunch (and press conference)

Second Session: The Human Genome Project

Moderator: James Wyngaarden

12:30 p.m. History of the Project: The Start Charles DeLisi
1988 - 1990 Bruce Alberts
1990 - present Maynard Olson
The ELSI Program Eric Juengst
1:30 p.m. Recorded vignettes IV
1:40 p.m. What have we found in the finished human sequence? Eric Lander
2:05 p.m. Break
2:25 p.m. Introduction to the Watson Lecture Lyle Dennis/Jim Watson
2:30 p.m. Watson Lecture: How the HGP has changed biology Shirley Tilghman

Moderator: Richard Gibbs

3:00 p.m. Recorded vignettes V
3:10 p.m. Beyond the Human Sequence
The Mouse Genome Bob Waterston
Comparative Genomics Eric Green
Functional Genomics Pat Brown
Computational Biology David Haussler
Variation David Bentley
4:30 p.m. The Road Ahead Ari Patrinos
4:40 p.m. A Vision for Genomics Research Francis Collins
5:00 p.m. Adjourn

Tuesday, April 15, 2003

Third Session: Implications of Genomics for Human Disease I

Moderator: (pending)

8:30 a.m.	Cancer	Janet Rowley
	Cardiovascular Disease	Rick Lifton
	Diabetes	Nancy Cox
	Infectious Disease	Adrian Hill
	Respiratory Disease	Fernando Martinez
9:45 a.m.	Questions and discussion	
10:10 a.m.	Break	

Fourth Session: Implications of Genomics for Human Disease II

Moderator: Michael Gottesman

10:30 a.m.	Language Disorders	Tony Monaco
	Hearing Disorders	Tom Friedman
	Vision Disorders	Val Sheffield
	Neurodegenerative Disorders	John Hardy
	Psychiatric Disorders	Aravinda Chakravarti
11:45 a.m.	Questions and discussion	
12:10 p.m.	Lunch	

Fifth Session: Implications of Genomics for Healthcare

Moderator: Raynard Kington

1:30 p.m.	Genomics and Therapeutics	Peter Goodfellow
	Genomic Health Care	Wylie Burke
2:20 p.m.	Questions and discussion	
2:45 p.m.	Break	

Sixth Session: Implications of Genomics for Society

Moderator: Ellen Clayton

3:05 p.m.	Genetics and Race	Harold Freeman
	Intellectual Property: Patenting and Licensing	Maria Freire
	Genetics and Disabilities	Paul Miller
	Forensic Genetics: Lessons from the World Trade Center	Bob Shaler
4:05 p.m.	Questions and discussion	
4:30 p.m.	Genomics and Global Health	David Weatherall
5:00 p.m.	Adjourn	

1/12/03 DRAFT

BRINGING THE GENOME TO YOU

April 15, 2003

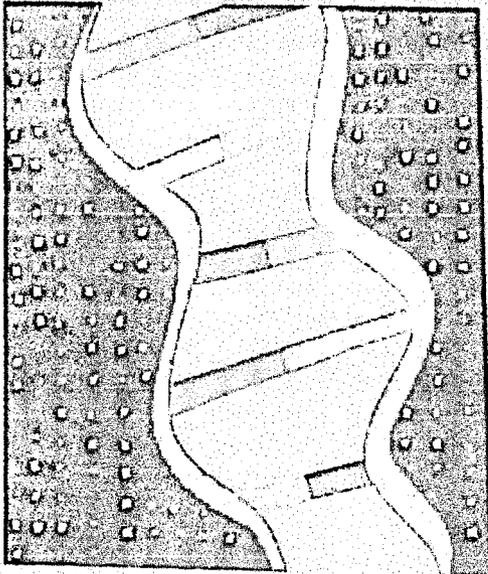
9:00 a.m. to 12:45 p.m.

Baird Auditorium - National Museum of Natural History, Washington, DC

Moderator: Robert Krulwich

9:00 - 9:10	Welcome	Tommy Thompson (invited) Spencer Abraham (invited)
9:10 - 9:20	Opening Remarks	James Watson
9:20 - 9:25	Opening Remarks	Francis Crick (recorded)
9:25 - 9:45	The Human Genome Project	Eric Lander
9:45 - 10:05	Human Genome Project to Medicine	Wylie Burke
10:05 - 10:25	The Media's View of the Genome	Robert Krulwich
10:25 - 10:45	Break	
10:45 - 12:15	Human Genome Project to Society	Moderator: Robert Krulwich
	Genetic Policy	Members of Congress (to be invited)
	Ethical Considerations	Tom Murray
	Consumer Interests	Kay Jamison
	Health Disparities	Harold Freeman
	Disabilities	Paul Miller
	Historical Issues	Vanessa Gamble
12:15 - 12:45	HGP and the Future	Francis Collins

CALL FOR POSTER ABSTRACTS



***NATIONAL INSTITUTES OF
HEALTH***

***NATIONAL INSTITUTE OF
NURSING RESEARCH***

SCIENCE SYMPOSIUM

**LINKING THE DOUBLE HELIX
WITH HEALTH:
GENETICS IN NURSING
RESEARCH**

**Cosponsored with:
Georgetown University School of Nursing and Health Studies
Johns Hopkins University School of Nursing
University of Maryland School of Nursing**

April 13, 2003

2:00 pm – 6:30 pm

Georgetown University School of Nursing and Health Studies

St. Mary's Hall

Washington, DC

Overview: The National Institute of Nursing Research is hosting a scientific symposium on genetics in nursing research. This half-day meeting will include podium presentations and a poster session. This meeting will provide an opportunity to showcase nursing research in genetics. Attendees will also have the opportunity to network with nursing colleagues and leaders in genetics nursing. Nurse investigators are invited to submit abstracts for poster presentations at this meeting, "Linking the Double Helix with Health: Genetics in Nursing Research". Posters should relate to the conference topic and research studies and research utilization projects are invited.

This meeting is planned to dovetail with other events at the National Institutes of Health being sponsored by the National Human Genome Research Institute (NHGRI) to commemorate the 50th anniversary of Watson and Crick's description of the double helix and the completion of the human genome sequence. Following the NINR meeting, attendees will want to plan on participating in the exciting two-day NGHRI symposium on Monday, April 14th and Tuesday, April 15th at Natcher Conference Center on the NIH

campus. More information on this meeting can be found on the NHGRI website at www.genome.gov by clicking on the April 2003 celebration link.

Speakers:

Patricia A. Grady, PhD, RN, FAAN
Director
National Institute of Nursing Research
National Institutes of Health
Bethesda, Maryland

Mary E. Kerr, PhD, RN, FAAN
Professor & Director
Center for Nursing Research
School of Nursing
University of Pittsburgh
Pittsburgh, Pennsylvania

Leslie G. Biesecker, MD
Senior Investigator
Genetic Diseases Research Branch
Director, Physician Scientist
Development Program
National Human Genome Research
Institute
National Institutes of Health
Bethesda, Maryland

Karen E. Dennis, PhD, RN, FAAN
Professor, Gerontology
School of Nursing
University of Central Florida
Orlando, Florida

Anita Yoemans Kinney, PhD, RN
Investigator, Huntsman Cancer Institute
& Associate Professor
College of Nursing
University of Utah
Salt Lake City, Utah

Janet Williams, PhD, RN, CPNP, CGC,
FAAN
Professor, Co-Director Post-doctoral
Fellowship in Clinical Genetics Nursing
Research
School of Nursing
University of Iowa
Iowa City, Iowa

Program Agenda:

- 2:00 – 2:20 Patricia Grady, PhD, RN, FAAN
Welcome
Genetics and Nursing: Moving the Science Forward
- 2:20 – 3:00 Leslie Biesecker, MD
Genomics and Grief: Using the Newest Technology to Address
One of the Oldest Needs- Experiences from the World Trade Center
Attack
- 3:00 – 3:30 Anita Yoemans Kinney, PhD, RN
Development and Implementation of BRCA1 Education, Counseling,
and Testing in African Americans
- 3:30 – 3:45 Break

- 3:35 – 4:15 Mary Kerr, PhD, RN, FAAN
The Quest in Understanding of Cerebral Ischemia: One Investigator's Journey
- 4:15 – 4:45 Karen Dennis, PhD, RN, FAAN
Incorporating Genetics in Nursing Research: The Importance of the Multidisciplinary Team
- 4:45 – 5:15 Janet Williams, PhD, RN, CPNP, CGC, FAAN
Integrating Genetics and Nursing Science to Improve Health
- 5:15 – 6:30 Research Poster Session

Contact Hours: The University of Maryland School of Nursing will award 4.7 contact hours. The University of Maryland School of Nursing is accredited as a provider of continuing education in nursing by the American Nurses Credentialing Center's Commission on Accreditation. Neither the University of Maryland School of Nursing nor the American Nurses Credentialing Center endorses or approves any products that may be associated with any continuing education activities.

Conference Fee: \$75

Directions to Georgetown University & Campus Map

<http://otm.georgetown.edu/directions.cfm>

<http://www.georgetown.edu/grad/prospective/map/map.html>

Registration Form

<http://www.nih.gov/ninr/news-info/geneventregis.pdf>

Guide for Abstract Submission

<http://www.nih.gov/ninr/news-info/geneventguide.pdf>

GENES, BRAIN, BEHAVIOR: BEFORE AND BEYOND GENOMICS

April 16, 2003 - NIH CAMPUS, WILSON HALL, BLG 1

Sponsored by NIMH, NINDS, NIA, NIDCD, NEI, NIAAA, NIDA

7:30 AM Breakfast

8:30 Welcoming Remarks - Francis Collins, NHGRI

Moderator: James F. Battey, Jr., NIDCD

GENETICS OF BRAIN DEVELOPMENT AND COMPLEX BEHAVIOR

8:45 Marc Tessier-Lavigne (Post-Genomic Approaches to Identify Brain Wiring Mechanisms)

9:30 Eric Kandel (Learning and Memory)

10:15 Break

10:30 Joseph Takahashi (Neurobiology of Circadian Rhythms)

GENETICS OF BRAIN DISORDERS

11:15 Robert Nussbaum (Parkinson Disease)

12:00 Lunch

1:00 Eric Nestler (Drug Abuse)

1:45 Howard Edenberg (Alcoholism)

2:30 Rudolph Tanzi (Alzheimer Disease)

3:15 Break

3:30 Huda Zoghbi (Rett Syndrome/Autism)

4:15 Stephen Warren (Fragile X Syndrome)

5:00 Geoffrey Duyk (Pharmacogenomics)

5:45 Adjourn

DRAFT

Genetic Variation and Gene-Environment (G-E) Interaction in Human Health and Disease

April 16, 2003

Masur Auditorium, NIH, Bethesda, MD

Sponsored by the National Institute of Environmental Health Sciences, the National Human Genome Research Institute and the National Institute of Alcohol Abuse and Alcoholism, National Institutes of Health

- 8:30-9:00 DNA Variations and Phylogenetic Considerations – An Overview
Eric Lander/Lynn Jorde/David Altshuler
- 9:00-9:30 SNPs and Haplotype Blocks/Whole Genome Approaches
David Cox/Debbie Nickerson
- 9:30-10:00 Influence of DNA Variation on Gene Expression
Jeff Trent/Chris Bradfield
- 10:00-10:15 BREAK
- 10:15-10:45 Relating Variation to Phenotype
Charles Rotimi
- 10:45-11:15 Monogenic Variation and Single Agent Exposure Including G-E Interaction
Clement Furlong
- 11:15-11:45 Complex Traits/Strategic Approaches
Mary Claire King/Nancy Cox
- 11:45- 12:15 Future use of DNA Variation in G-E Interaction Research on Complex Traits
Avavinda Chakravarti/David Altshuler
- 12:15-12:30 Audience Participation and Discussion

Symposium organizers: Dr. Samuel Wilson, NIEHS and Dr. Lisa Brooks, NHGRI

Funding for Human Genome Project Co-Funded by NIH and DOE
(\$ in millions)

3.7 13

	FY 1990 Actual	FY 1991 Actual	FY 1992 Actual	FY 1993 Actual	FY 1994 Actual	FY 1995 Actual	FY 1991 - FY 1996 Actual	FY 1997 Actual	FY 1998 Actual	FY 1999 Actual	FY 2000 Actual	FY 2001 Actual	FY 2002 Actual	FY 2003 Amd PB	Total Funding FY1991-2003
NIH (w/o DIR)	59.5	87.4	104.8	106.1	107.6	113.9	127.6	145.2	171.5	226.7	271.0	308.3	345.2	369.3	2,484.7
DOE 1/	27.2	47.4	59.4	63.0	63.3	68.7	73.9	78.9	84.9	88.8	87.5	85.5	90.1	76.8	968.2
Total	86.7	134.8	164.2	169.1	170.9	182.6	201.5	224.1	256.4	315.5	358.5	393.8	435.3	446.1	3,452.9
BRDPI in FY 1991 Dollars	1.0	1.000	1.044	1.080	1.122	1.160	1.190	1.223	1.265	1.311	1.368	1.426	1.477	1.524	
		1991				1995					2000			2003	
NIH in 1991 Dollars	59.5	87.4	100.4	98.2	95.9	98.2	107.2	118.7	135.6	172.9	198.1	216.2	233.7	242.3	
DOE in FY 1991 Dollars	27.2	47.4	56.9	58.3	56.4	59.2	62.1	64.5	67.1	67.7	64.0	60.0	61.0	50.4	
Total in FY 1991 Dollars	86.7	134.8	157.3	156.5	152.3	157.4	169.3	183.2	202.7	240.6	262.1	276.2	294.7	292.7	
	1990					1995					2000			2003	
Cumulative total, 199	0.0867	0.2215	0.3788	0.5353	0.6876	0.8450	1.0143	1.1975	1.4002	1.6408	1.9029	2.1791	2.4738	2.7665	
Cumu. NIH in 1991 Dollars	0.0595	0.1469	0.2473	0.3455	0.4414	0.5396	0.6468	0.7655	0.9011	1.0740	1.2721	1.4883	1.7220	1.9643	
Cumu. DOE in 1991 Dollars	0.0272	0.0746	0.1315	0.1898	0.2462	0.3054	0.3675	0.4320	0.4991	0.5668	0.6308	0.6908	0.7518	0.8022	

1/ DOE figures do not include salaries and expenses of DOE employees devoted to this effort.

2/ Constant FY 1991 comparison dollars verified per NIH Economist and adjusted on Jan. 10, 2003.

758.3 555.2