


[Interviews with Botstein (Genentech) and Davis (Stanford University) January 1987, a. B. G., August 1988].


ADA regs (1991). The ELSI working group urged EEOC to circumscribe health inquiries to only those questions that would elicit information about conditions that would affect job performance. The proposed regulations indicated that employers could obtain the full medical record, but could only use information that was job-related to reject a job applicant. This shifted power to the employer and took power away from the prospective employee. To assert discrimination, an individual would have to prove that the reason he or she was rejected was not job related, but the job applicant would have supplied vast amounts of information with little knowledge of how it was used by the employer. If, however, the employer never had medical information beyond that relevant to job performance in the first place, then arbitrary decisions could not be masked. This would increase the effort necessary on the part of employers to define what job-related questions to ask, and on those responding to employer requests, as they would have to filter the medical record rather than ship it out whole. It implied a major change in standard practice, but one in harmony with the ADA statute.


additional witnesses Two additional witnesses gave excellent testimony, but the action centered on exchanges between Rep. Wise, Bernadine Healy, and James Watson. W. French Anderson also came from NIH; Philip Reilly, director of the Shriver Center for Mental Retardation in Waltham, MA, spoke about activity in the States, concerns of the American Society for Human Genetics, and general principles to be considered in possible legislation. He also noted the likelihood of large databases generated from DNA typing in the criminal justice system. Paul Billings, from the California Pacific Medical Center, gave general background on genetic discrimination and sketched out a few specific cases for the committee.

Adler, R. (1992). Adler quoted the 1988 OTA report that stated “genome projects raise no new questions of patent or copyright law” and went on to speculate that “contributing to this lack of foresight may have been an urgency to start the genome program.” As author of the offending OTA sentence, I admit to embarrassment about such a bold and misleading oversimplification in the summary chapter. The unfortunate result was to distract from a subsequent chapter on technology transfer in the 1988 report that considered the issues in considerably more depth. The lack of foresight was not quite as bad as alleged. OTA urged early filing of patent applications. Failure to do so could “inhibit full exploitation of an invention” and invited “foreign exploitation of research funded at US taxpayers’ expense… Penicillin was discovered in England, but the patent was obtained by US corporations … the United Kingdom claimed the Nobel Prize, but the United States reaped most of the economic benefits.” OTA also noted “there is a gray area between invention of new methods and the data that result from using them,” but did not predict how DNA sequences themselves, of the sort at issue in the NIH patent application, would become the subject of patent controversy. Like scientists, public policy analysts can be humbled by the march of events.

Adler, R. and R. Eisenberg (1992). Adler pointed to how sequences might be used to identify a tissue of origin. Rebecca Eisenberg noted the NIH application listed uses for forensic identification or as genetic markers. Just as the use of DNA markers for identification were useful only if population frequencies were known, all these uses would also require a great deal more to be known about the population distribution of the sequences, or how different tissues expressed them. Since Venter’s laboratory was identifying the genes for the first time, or they would not be novel, such information was by definition unavailable without further work. An added problem was that coming from protein-coding regions, their use for forensic typing would make these precisely the regions most likely to later prove related to a genetic disorder, making them poor candidates for general use because of the ethical problems this would raise. This does not, however, count against the contention that the sequences might someday be useful for something.


Advisory Committee on the Human Genome (1992). A Genome Program in Canada, Summary sheet of the committee’s recommendations prepared for the Canadian Cabinet by Charles Scriver.


Alberts, B. (1990). Interview, University of California at San Francisco.


Avery, O. T., et al. (1944). "Induction of Transformation by a Desoxyribonucleic Acid Fraction Isolated from Pneumococcus Type III." J. Exp. Med. 79 (1 February): 137-158.


Bayev, A. A. (1989). Early in the 1930s, Bayev took courses from V. N. Slepkov, whose brother was associated with Bukharin, whom Stalin came to see as a dangerous rival. Graduate students who had studied under Slepkov were rounded up and sent to prison. By such tenuous connections were many lives shattered.


Bayev, A. A. (1990). Interview, Englehardt Institute for Molecular Biology, planning meeting for June 1990 international meeting on ethical, legal and social issues related to genome research in Bethesda, MD.


Beauchamp, T. (1986-1991). Kennedy Institute of Ethics Tuesday seminars, electronic mail communications, and conversations, Department of Philosophy, Georgetown University; Beauchamp was on the staff of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research.


Berg, P. (1990). Note to author, commenting on a meeting of the Committee to Study Decisionmaking, Institute of Medicine, Beckman Center, Irvine California. March S. University.


Berg, P. and L. Lerman (1992). Letter to Dr. Frank Press, President of the National Academy of Sciences, Chairman, NIH Program Advisory Committee on the Human Genome (Berg) and Acting Chairman, DOE Health and Environmental Research Advisory Committee (Lerman).

Berg, P. and L. Lerman (1992). Letters to Dr. Frank Press and Dr. Bernadine Healy, Chairman, NIH Program Advisory Committee for the Human Genome; Acting Chairman, DOE Health and Environmental Research Advisory Committee; Co-chairman and Acting Co-chairman, NIH-DOE Joint Subcommittee.


Budget tables for NIGMS genetics program (1992). By this reasoning, $25 million, or just over 10 percent of the NIGMS genetics program, moved away with the genome center. Some unknown fraction of the science supported by the genome center would likely have been supported by NIGMS, but certainly not all. It seems likely that some would instead have gone for study of gene regulation, recombination, and other basic genetics.
Budget tables for NIGMS genetics program (1992). The year NIH first had a special genome budget, the Genetics Program Branch at NIGMS saw a budget increase from $188.9 million (1987) to $213.8 million (1988). In 1989, when the genome project left NIGMS, the Genetics Program Branch budget went down to $209.6 million, and it dropped again to $207.8 million in 1990, before rebounding to $218.3 million in 1991 and an estimated $229.5 million in 1992. During these same years, the NIH genome budgets were: $17.2 million (1988, within NIGMS); $28.2 million (1989); $59.5 million (1990); $87.4 million (1991); and $104.9 million (1992 estimate). The 1993 increase was even larger than shown, as the GenBank contract amount of roughly $4 million was transferred to the National Library of Medicine.


Burris, J. (1991). Electronic mail note to the author, National Academy of Sciences, Washington, DC. The check arrived from the McDonnell Foundation two days after the project was approved by the NAS Governing Board.


Bush, G. (1990). Text of Remarks by the President at the Annual Meeting of the National Academy of Sciences, Office of the Press Secretary, the White House.


By these same proportionate estimates "Italy’s contribution was 29 percent that of the US, the UK’s 66 percent, the USSR’s 78 percent (at official exchange rates, but only 5 percent at unofficial Fall 1990 “black market” rates). Those without specific
genome programs could not be calculated. US figures are for the NIH and DOE programs. Japanese figures include the Monbusho, STA, and Department of Health programs, but not agricultural or related MITI programs. The UK figure is for the combined MRC-ICRF program, and Italy’s includes only the Ministry of Science figures. GNP figures for these calculations are taken from the 1990 World Almanac (NY: Pharos Books) and The Statesman’s Yearbook, 1989-1990 (NY: St Martin’s). Unofficial conversion rates for Rubles taken from black market rate, Leningrad and Moscow, June 1989. My estimates for Japan’s funding are higher than those of the Department of State ($3.5 million), which did not account for differences in budgeting practices for personnel and space. My calculations assumed that 40 percent of US research budgets covered salaries and other expenses not included in the European and Japanese budget items. Genome budget estimates for 1990 are taken from various references that follow.”

Byrnes, M. (1990). Phone conversation, National Commission on AIDS, referring to period when Dr. Byrnes was staff to Senator Lowell Weicker, Committee on Appropriations, US Senate.


Cahill, G. (1988). Interview, Howard Hughes Medical Institute, Bethesda, MD.


Capron, A. M. (1983-1993). Conversations connected with Office of Technology Assessment activities, Institute of Medicine activities, the Biomedical Ethics Advisory Committee, and other events, University of Southern California; Capron was consultant to the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research and the Ethics Advisory Board (Department of Health, Education and Welfare); Executive Director of the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research; and chair of the Biomedical Ethics Advisory Committee.


Church, G., et al. (1987). Invited speakers to the Committee on Mapping and Sequencing the Human Genome, Board on Basic Biology, National Academy of Sciences.


Collins, F. S. (1993). Note to author, National Center for Human Genome Research, NIH.


Coutelle, C. (1990). Interview at meeting of UNESCO Director General’s Scientific Coordination Committee on Human Genome Research, Englehardt Institute for Molecular Biology, Moscow.


DeLisi, C. (1990). "DeLisi left DOE employ 1 September 1987, two years after joining it, to chair a department of mathematical biology at Mt. Sinai Medical Center in New York City. He left that post in January 1990 to become Dean at the College of Engineering, Boston University."


DOE initial cost estimates (1986). "The DOE-OMB agreement is dated 18 December 1986. DeLisi had briefed OMB in July and got a preliminary go-ahead signal on 5 September. DeLisi thus cut his deal some time before HERAC reported. Indeed, he reported to the HERAC subcommittee at its meeting on 6 and 7 November (in Denver) that he had reprogrammed several millions of dollars in fiscal year 1987 and expected a $20 million annual budget two years hence. While they did not influence the initial DOE plans, the HERAC subcommittee’s budget figures were to figure in the larger budget debate that developed later."


Domestic Policy Council (1987). Subcommittee on Characterization of Complex Genomes, list of questions to be asked of agencies, White House.


Dulbecco, R. (1990). Interview, Salk Institute, La Jolla, CA.


Fink, L. (1990). NCHGR Bioethics Program Addresses Social and Ethical Implications of Knowledge about Human Genes, National Center for Human Genome Research, NIH.


Fletcher, J. C. (1986). Memo to Ruth Kirschstein, Director, National Institute of General Medical Sciences, Magnuson Clinical Center, NIH.


foreign commissions The British Warnock Report touched on genetics in several of its recommendations. The German Benda Commission proposed a broad set of laws to cover gene therapy, embryo research, and genetic technologies. This was followed a few years later by a report from the Enquete Commission of the German Parliament, and ultimately led to new German statutes governing scientific research. The French government considered a report on ethics and the life sciences, and produced legislation to protect human subjects of research. The Glover Report to the European Commission included a section on handicaps that discussed the role of genetic testing. A January 1990 genome conference in Paris devoted a session to discussion of eugenics, and scientists’ responsibilities in genome research. Santiago Grisolia’s second conference in Valencia was entirely devoted to discussion of the social implications of genome research. And finally, the Council of Europe’s Ad Hoc Committee of Experts on Bioethics (CAHBI) worked towards reports on the use of genetic testing and screening in medicine and on DNA testing in the criminal justice system.


Frye v. United States (1923). 293 F. 1013, District of Columbia Circuit Court.


Second report of chrn 21q21 assoc with FAD, 4 families


Of 8 tRNA-tyr genes in S. cerevisiae, found 8 dif restr frags. Sup4-o (ochre suppressor mutant) linked to one of these variants. Sup4 gene and two other tRNA-tyr genes cloned. Used RFLP fragments for cloning (in lambda), hybridized to find tRNA-tyr genes, then M-G sequenced from Xma I site at 3' end of gene; recloned in pBR 322, which has no Xma sites, and thus was used for sequencing. Sequenced approx 20 bp to 5' end, through 150 bp gene (incl 14-bp intron), and 40-60 bp 3' to gene. Found GC to AT mutation in Sup4-o at position 37 in tRNA that was wobble position in anticodon. Also found 14 bp intron in all 3 genes, just 3' to anticodon triplet in all 3, but terminology 'intron' not yet used (although did cite Roberts and Sharp papers, and Tilghman in press). Basically, used RFLP to localize, and tool to isolate gene for sequencing.


Grisolia, S. (1982). Recollections, University of Kansas Medical Center, College of Health Sciences and Hospital.


Health and Welfare program Akira Ooya was the principal scientist for the Ministry of Health and Welfare program, which was budgeted for ¥460 in 1991. Of this amount, ¥100 million ($740,000) supported a cell line repository and the bulk of the remainder was for scientific grants [Matsubara, 1992 #1086].


Healy, B. (1992). Interview, Building 1, Room 126 (Director’s Office, National Institutes of Health).


HUGO Originators (1988). Walter Bodmer (Imperial Cancer Research Fund, London), Sydney Brenner (Medical Research Council, UK), C. Thomas Caskey (Baylor University, USA), Jean Daussel (Centre d'Etude du Polymorphism Humain, Paris), Renato Dulbecco (Salk Institute and Italy), Leroy Hood (Caltech, USA), Kenichi Matsubara (Osaka, Japan), Frank Ruddle (Yale, USA), John Tooze (EMBO), James D. Watson (Cold Spring Harbor, USA), and Harold Zur-Hausen (Germany). letter about founding the Human Genome Organization.


Human Genome Organization (1992). "HUGO Position Statement on cDNAs: Patents." *G-Nome News*(Number 9, March 1992): 2-3. The HUGO statement did not "oppose patenting of useful benefits derived from genetic information. HUGO does, however, oppose the patenting of short sequences from randomly isolated portions of genes encoding proteins of unknown function...The filing and approval of genome patents, whether in this particular case or in other types of genome patent cases, must incorporate global perspectives.

It is HUGO's position, therefore, that the US EST patent applications should not be approved. We join the American Society of Human Genetics in supporting this view.

The Human Genome Project is a major scientific area that now depends heavily on international cooperation in order to avoid both costly competition and duplication of effort...it is the entire spectrum of international scientific collaboration that may be jeopardised. HUGO therefore urges a quick resolution to the EST case.
HUGO urges the development of a process that allows for flexible negotiation and also mediation between the potentially conflicting needs of different scientific communities. Scientists, policy-makers and administrators world-wide must work together and accept responsibility for balancing the many competing priorities.


Industrial Biotechnology Association (1987). Results of the IBA Membership Survey on Mapping the Human Genome, Government Relations Committee, IBA.


Inter-Council Human Genome Advisory Committee (1991). Report to the Granting Councils: Medical Research Council; Natural Sciences and Engineering Research Council; Social Sciences and Humanities Research Council; and the Secretary to the Advisory Committee, Dr. Lewis Slotin, Medical Research Council.


Rabbit liver DNA-EcoRI, Pst I, or KpnI; frags denatured, electrophoresed, blotted, hybridized with beta-blogin cDNA. Determined restriction map, orientation of expression, and estimated only one gene copy/genome by ration of gene DNA to total DNA. One of first uses of physical mapping techniques in mammalian genome.


Jonsen, A. (1985-1992). Conversations at Institute of Medicine activities and other events, University of California, San Francisco and then University of Washington, Seattle; Jonsen was a commissioner on both the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research and the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research.


King, P. (1987-1992). Conversations at meetings of the ELSI working group, Institute of Medicine activities and other events, Georgetown Law School; King was a commissioner on both the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research and the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research; she then served on the NIH Fetal Tissue Transplantation Research Panel and the NIH-DOE Working Group on Ethical, Legal, and Social Issues, as well as on several Institute of Medicine committees and other panels.


Levinson, R. (1990). Phone interview, Office of Science and Technology Policy, the White House.


Mammalian Genetics Study Section (1990). Summary Statement evaluating grant proposal R01 DK 43425-01, National Institutes of Health.


Mayor (1989). Fellow Spaniard Grisolia was appointed chair, and the committee included representatives from Chile, France, Germany, Japan, Kenya, Thailand, Tunisia, the United States, and the USSR. Organizational representatives were designated by several international scientific organizations in biology, adding observers from Belgium, France, Israel, and Italy. UNESCO Headquarters, Paris.


McCormack, S. (1998). Among 1980-1993 patents in the DNA Patent Database that have been read and coded, 24% are assigned to universities (15% private and 9% public); 14% to private nonprofit research centers; and 53% to private firms (46% pharmaceutical or biotechnology and 7% other companies or unknown). The DNA Patent Database started from a collection of nonplant DNA-based patents identified by the US Patent and Trademark Office (James Martinell, examiner) and the Office of Technology Assessment (Erica Rose, Kathi Hanna, and Robyn Nishimi, OTA staff) that were given to the Kennedy Institute of Ethics (LeRoy Walters, director) when OTA ceased operations. Stephen McCormack and Robert Cook-Deegan read those patents, eliminating some that are not DNA-based, and developed a coding scheme. The collection has since been expanded through 1997, but patents 1994-1997 have not yet been read and coded. All patents in the collection are available in full text format on the World Wide Web through the Foundation for Genetic Medicine at http://www.geneticmedicine.org/. Data analyzed by Stephen McCormack, DNA Patent Database, Foundation for Genetic Medicine and Kennedy Institute of Ethics.


McKusick, V. A. (1988). Memo to Sir Walter Bodmer, Dr. Sydney Brenner, Dr. J. [sic] Thomas Caskey, Prof. Jean Dausset, Dr. Renato Dulbecco, Dr. Leroy Hood, Dr. K. Matsubara, Dr. Frank Ruddle, Dr. John Tooze, Dr. James D. Watson, and Dr. Harold Zur-Hausen, Johns Hopkins University.


Mirzabekov, A. (1989). Interview, Guest Quarters, Bethesda, MD, in association with a meeting at the National Center for Human Genome Research.

Mirzabekov, A. (1990). Interview, Englehardt Institute for Molecular Biology, Moscow, in conjunction with a meeting to plan an international conference on ethical, legal and social issues in genome research in Bethesda, MD in June 1991.

Mishkin, B. (1983–1991). OTA workshop on impacts of neuroscience (1983), a meeting on prospects for a bioethics commission convened for Elizabeth McClosky, staff to Senator Danforth (1989), and various phone and personal conversations concerning federal bioethics commissions, Hogan & Hartson, Washington, DC; Mishkin was on the staff of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, the Ethics Advisory Board (Department of Health, Education and Welfare), and the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research.


Monbusho budget Matsubara tried to secure a ¥6.5 billion budget ($43 million) to support two five-year projects under Monbusho [Matsubara, 1990 #1451; Matsubara, 1990 #1457; Matsubara, 1990 #1455; Ministry of Education Science and Culture, 1990 #198]. The first year’s budget was ¥400 million ($2.7 million) for the biology program. A second, separate but related, program focused on informatics. A new Genome Analysis Center would be established at the University of Tokyo, with a national research group and a five-year commitment (first year budget ¥220 million, or $1.5 million). This was to be the first installment on a much larger program. The Monbusho plan laid out a strategy for genome research, urging establishment of groups in five areas: 1) physical and genetic mapping, 2) analysis of complementary DNA collections (cDNA, representing those parts of DNA transcribed to RNA and representing the expressed parts of genes), 3) pursuit of new techniques to analyze DNA, 4) informatics, and 5) science and society. The Monbusho proposal set aside funds for international scientific workshops and for training of postdoctoral fellows and other research personnel [Matsubara, 1991 #1456; Ministry of Education Science and Culture, 1990 #198].

Monbusho cuts This was roughly ¥200 million ($1.5 million ) short of Matsubara’s aspirations for Monbusho. The five elements remained, led by Matsubara (Osaka University), Mitsuaki Yoshida (Tokyo University), Minoru Kanehisa (Kyoto University), with a smaller program at Kyushu University [Matsubara, 1992 #1086].


Moscowitz, J. (1987). Note to Dr. Wyngaarden, attached memo. Also used as briefing material by NIH for congressional staff and at genome meetings., National Institutes of Health.


National Science Foundation (1988). The Science and Technology Resources of Japan: A Comparison with the Untied States, National Science Foundation.

Nature (1992). The editorial might have been more persuasive if it had gotten Healy's name right.


NIH Grant proposal R01 DK 43425-01 (1990). Evaluation of Carrier Screening for Cystic Fibrosis, Grant Application to the National Institutes of Health. Name of the principal investigator withheld on request.


NRC Committee members (1988). Phone and personal interviews, Office of Technology Assessment.


Office of Human Genome Research (1989). Ethical and Legal Studies Relating to the Program to Map and Sequence the Human Genome, National Institute of General Medical Sciences, NIH.

Office of Program Planning and Evaluation (1987). The Human Genome, 54th Meeting of the Advisory Committee to the Director, National Institutes of Health.


OMB Briefing (1986). The budget briefing documents for the OHER-OMB meetings included budget projections for fiscal years 1987-90 of 5.64, 11.55, 18, and 22 million dollars. The cover sheet for the DOE document to OMB specified a four year project starting October 1, 1987, extending to September 30, 1991, and costing 95 million dollars. By simple arithmetic, the fiscal year 1991 budget must have been projected at 40 to 45 million dollars. Decisions about a Phase II budget were to be made in 1990 and 1991.


Used RFLP to dx delta-beta thalassemia in fetus by amniotic fluid. confirmed fetoscopic blood sample and protein analysis. Also confirmed at birth.

Showed deletion of alpha globin in alpha-thal, using S blot and RFLP analysis (showed missing fragments)

Showed deletion of beta-globin and beta-globin-like sequences in dealta-beta-thal and HPFH (i.e. hybridized to beta-globin probe) sequences by missing restriction fragments.

Kan had already shown alpha-globin del by hybridization in solution. They used S blot, technically easier and also able to pick up more subtle changes, like loss of fragments (rather than complete absence of hybridizing sequences).

Used alpha and beta-hemoglobin probes; enzymes were Eco RI and Hin dIII


Palfreman, J. (1989). The Book of Man Horizon, BBC, and NOVA, WGBH.


Peterson, J. (1989). Notes from presentation at Genes and Machines, II (New Hampshire conference on DNA and computers), National Center for Human Genome Research.

Used RFL to track inheritance of strains heterozygous for ribosomal DNA variants. Size of Eco RI fragments. Suggested that at least 90 percent of the est 100-140 rDNA genes were on a single chromosome (from others' work, on chrm I). Showed suppression of meiotic recombination in this region. Twelve of 14 variants examined showed no recombination of rDNA regions. 2 of 14 showed mitotic, not meiotic, recombination (distinguished by finding nonreciprocal recomb). Diploid strain from Lee Hartwell cleaved by Eco RI, DNA-DNA hybridization to rDNA probe.


Philosopher Michael Walzer of Princeton, wrote a classic essay in 1973 about the dilemma of “dirty hands,” when pursuit of political power and moral virtue came into conflict.

Pines, M. (1986). *Shall We Grasp the Opportunity to Map and Sequence all Human Genes and Create a ‘Human Gene Dictionary’*. Prepared for a meeting of the Trustees of the Howard Hughes Medical Institute, Bethesda, MD, Howard Hughes Medical Institute.


President's Council on Competitiveness (1991). Report on National Biotechnology Policy, The White House. Ernst & Young Estimated that federal funding was $3.7 billion in 1991, with $3.2 billion industrial investment in R&D, as cited in the National Research Council Report by the Committee on Japan. The Japanese corporate contribution was estimated at 276 billion yen ($2 billion) that same year (see footnote 5 in NRC report), while government funding was ¥89.6 billion ($665 million) (see table 2 in NRC report). Yen to dollar rates are calculated at 135¥/$ in 1991, 150 ¥/$ in 1990, here and throughout the chapter.


Program Advisory Committee on the Human Genome (1990). Resolution from the NCHGR Program Advisory Committee on the Human Genome, National Institutes of Health.


Public Law 96-517 (1980).


Report reviewer (1988). Interview with individual who reviewed the NRC committee's report, whose name is withheld to preserve anonymity, Office of Technology Assessment.


Volga German families, including Eisenach and Reiswig, fail to show linkage to chrm 21 markers in 14 kindreds.


Schneider, J. (1992). Memorandum to the author, Office of the Director, NIH.


Schneider, J. (1993). Interview, Building 1; discussing a February 1991 electronic mail message from Rob Lanham, NIH Counsel, to William Raub, then acting director, NIH, and a letter from William Raub to James Watson, Office of the Director, National Institutes of Health. The February 1991 memo did not assert a conflict of interest, but rather referred to a possible “appearance of conflict,” based on stock purchases since Watson’s 1990 disclosure statement. The argument of “appearance of conflict,” while retaining surface plausibility and potential for public relations mischief, was quite different from the kind of conflict associated with a clinical trial. A clinical trial centered on a drug or device nearing market approval. The results of a trial bore directly on prospects for Food and Drug Administration approval of a new drug, and such approval for a major new drug could make the stock of even a pharmaceutical giant rise dramatically, if successful, or plummet, if unsuccessful. Genome research, in contrast, was in most cases quite distant from commercial application. There were a few exceptions, in the areas of research instrumentation or DNA diagnostics. It was nonetheless difficult to imagine how the results of a grant decision or research initiative on gene mapping could have any substantial impact on the stock of any but the smallest and most targeted genome research company. Conflict might indeed have arisen if a small instrumentation firm or DNA forensics company sought Small Business Innovation Research funding, or a similar scenario. Watson’s holdings, however, were not in such companies, but in large pharmaceutical houses whose stock would be almost entirely unaffected by the fate of federal genome research decisions in the short run. They might benefit from the general knowledge emanating from NIH genome research, but this would not fall into the usual definition of conflict of interest. In retrospect, the February 1991 memo appears to be one lawyer’s cautious and broad interpretation of the possibility of an “appearance” of conflict, coupled to a narrow definition of permissible behavior, Office of the Director, National Institutes of Health.


Search committee (1992). Healy appointed a committee to assist in the search for Watson’s successor. The committee roster was included in a press packet distributed at a press conference down the hall from the NIH Director’s office. The committee was co-chaired by Ruth Kirschstein, Director of the National Institute of General Medical Sciences, and George Vande Woude, a former National Cancer Institute intramural researcher and current investigator at Advanced Bioscience Laboratories. The other members were Raphael Daniel Camerini-Otero, National Institute of Diabetes and Digestive and Kidney Diseases; Daryl A. Chamblee, Senior Policy Advisor and Counselor to the Director, NIH; Gary Felsenfeld, National Institute of Diabetes and Digestive and Kidney Diseases; Martin Gellert, National Institute of Diabetes and Digestive and Kidney Diseases; Jay Moskowitz, Associate Director for Science Policy and Legislation, NIH; Maynard Olson, Washington University; David Rodbard, Division of Computer Research and Technology, NIH; Phillip A. Sharp, Massachusetts Institute of Technology; Maxine Singer, Carnegie Institution of Washington; Shirley M. Tilghman, Princeton University; and Nancy S. Wexler, Hereditary Disease Foundation and Columbia University, National Institutes of Health.


Sinsheimer, R. (1985). Letters to Donald Sharp Fredrickson, President, Howard Hughes Medical Institute, University of California, Santa Cruz.


Stryker, J. (1984-1993). Conversations, Office of Technology Assessment and the University of California, San Francisco; Stryker was a member of the staff for the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research and subsequently at the Office of Technology Assessment and the National Research Council.


Syvanen, M. (1990). Letter signed by Chuck Turnbough, University of Alabama; Michael Syvanen, University of California, Davis; Richard Calendar, University of California, Berkeley; Ryland Young, Texas A&M University; Cathy Squires, Columbia University; and Marlene Befort, New York Public Health, BIONET electronic bulletin board.


That process was complex "That process was complex and contentious in itself, involving not only the National Institute of General Medical Sciences and NLM, but also the NIH genome office, the DOE genome office, the GenBank group at Los Alamos, and the Howard Hughes Medical Institute."


The critical problem "The critical problem was to create and maintain temperatures high enough to ignite the same reactions that take place in the sun and other stars. In work with C. J. Everett, Ulam pioneered the use of the “Monte Carlo” method to model how Teller’s scheme for doing this would play out. The Ulam-Everett calculations showed the reaction would fizzle before generating an explosion. The Monte Carlo technique was a way to simulate complex phenomena mathematically. It was
useful in characterizing an enormous range of applications, and had vast practical implications well beyond the hydrogen bomb simulations. The Ulam-Everett calculations predated the ready availability of computer technology needed to make Monte Carlo models generally practical. The fusion reaction calculations were nonetheless among the earliest and most historically significant demonstrations of the technique."


unnamed (1991). Interview with a member of the initial review group (study section) that scrutinized the grant. Name withheld to protect confidentiality, Meeting at Cold Spring Harbor Laboratory.

unsigned (1987). Draft letter to go from the Secretary of Health and Human Services to J. Bennett Johnston, National Institutes of Health.


US Senate (1982). Nominations, Committee on Labor and Human Resources.


Harkin: I think there is more support here than you may think (p. 1150).


Wada, A. (1985). Letter to Professor Paul Doty upon his retirement, University of Tokyo.


Watson sat on the scientific board of two companies (Diagnostic Products Corporation, Pall Corporation), a research institute (Roche Institute of Molecular Biology), consulted for Diagnostic Products Corp., and held stock in Genetics Institute, Oncogene Science, Amgen, Beecham, Smith-Kline, Diagnostic Products Corp., Glaxo, Eli Lilly, Merck, Pall, and other companies.


Watson, J. D. (1987). Interview, Cold Spring Harbor Laboratory, Director’s office.


Watson, J. D. (1988). Disqualification from Activities that would Affect My Financial Interests, Memo to William F. Raub, Deputy Director, NIH.


Watson, J. D. (1989). Disqualification from Activities that Would Affect My Financial Interests, Memo to William Raub, Acting Director, NIH.

Watson, J. D. (1989). Disqualification from Activities that would Affect My Financial Interests, Memo to William F. Raub, Deputy Director, NIH.


Watson, J. D. (1990). Conversations about Japan following author’s return from a trip there, Cold Spring Harbor Laboratory, NY, and National Center for Human Genome Research, Bethesda, MD.


Watson, J. D. (1992). Interview. Watson recalled receiving a letter from William Raub that sought information about certain stock purchases. He and Raub had then met with Jack Kress in May of 1991, after Healy had become director of NIH and before Raub left NIH to join the White House Office of Science and Technology Policy. Kress had indicated he would follow up if Watson’s activities required a response, Cold Spring Harbor Laboratory.


While Venter was confident "While Venter was confident of his capacity to attack a genome region of several million base pairs, the longest continuous sequence from his laboratory was in the tens of thousands. It had just been completed as his proposal came up for review. At the time, many scientists were skeptical that a further increase in scale was possible without major technical improvements in the technology, especially in the analytical software. A critical question was how short sequences of 300 to 500 base pairs, whether generated by machines or manual methods, would be pooled into long stretches of sequence millions of bases long. This was a problem that no laboratory had yet solved, and many believed it was premature to try on a massive scale, particularly on the human genome. Human DNA had many regions containing long repeated sequences, and these might prove to be impenetrable barriers to analysis.”.


White, T. (1992). Interview with Paul Rabinow, Department of Anthropology, University of California, Berkeley, presentation at Rice University.


Wilfond, B. S. and N. Fost (1990). Cystic Fibrosis Heterozygote Detection: The Introduction of Genetic Testing into Clinical Practice, Program in Medical Ethics, University of Wisconsin.


Yesley, M. S. (1988-1992). Interviews and conversations at meetings, Los Alamos National Laboratory, ELSI working group meetings, and elsewhere; Yesley was Executive Director of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, which operated from 1974-1978.


