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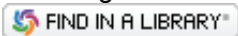


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Lifton, Richard P.

Individual genomes on the horizon. [editorial]

New England Journal of Medicine 2010 April 1; 362(13): 1235-1236



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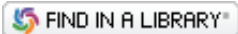


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Lumley, Thomas; Rice, Kenneth

Potential for revealing individual-level information in genome-wide association studies.

JAMA: The Journal of the American Medical Association 2010 February 17; 303(7): 659-660



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Article Document 3

Via, Marc; Gignoux, Christopher; Burchard, Esteban González

The 1000 Genomes Project: new opportunities for research and social challenges

Genome Medicine [electronic] 2010 January 21; 2(1): 3p. Accessed: <http://genomemedicine.com> [2010 February 24]



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<http://genomemedicine.com> (link may be outdated)



Article Document 4

Marturano, Antonio

When speed truly matters, openness is the answer.

Bioethics 2009 September; 23(7): 385-393

Abstract: In this paper I analyse the ethical implications of the two main competing methodologies in genomic research. I do not aim to provide another contribution from the mainstream legal and public policy perspective; rather I offer a novel approach in which I analyse and describe the patent-and-publish regime (the proprietary regime) led by biologist J. Craig Venter and the 'open-source' methodologies led by biotechnology Nobel laureate John Sulston. The 'open-source methodologies' arose in biotechnology as an alternative to the patent-and-publish regime in the wake of the explosion in computer technology. Indeed, the tremendous increase in computer technology has generated a corresponding increase in the pace of genomics research. I conclude this paper by arguing that while the patent-and-

publish method is a transactional method based on the exchange of extrinsic goods (patents in exchange for research funds), the free and open-source methodology (FLOSS) is a transformational method based on a visionary ideal of science, which leads to prioritizing intrinsic goods in scientific research over extrinsic goods.



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<http://www3.interscience.wiley.com/journal/122527835/issue> (link may be outdated)



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Technology lowers cost of decoding a genome to \$50,000 [news]

New York Times 2009 August 11; p. D3



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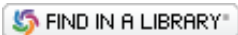


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Nerlich, Brigitte; Hellsten, Iina

Beyond the human genome: microbes, metaphors, and what it means to be human in an interconnected post-genomic world

New Genetics and Society 2009 March; 28(1): 19-36



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What's race got to do with it?

Newsweek 2009 January 12; 153(2): 16



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My genome, My self: In the coming era of consumer genetics, your DNA will have much to tell you about the biological bases of your health, your physique and even your personality. But will this knowledge really amount to self-knowledge?

New York Times Magazine 2009 January 11; p. 24-31, 46, 50



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<http://www.nytimes.com> (link may be outdated)



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Ethical, legal, and social considerations in conducting the Human Microbiome Project.

Genome Research 2008 December; 18(12): 1861-1864



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Zwart. Hub

Understanding the Human Genome Project: a biographical approach

New Genetics and Society 2008 December; 27(4): 353-376

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Haas, David M.; Renbarger, Jamie L; Meslin, Eric M.; Drabiak, Katherine; Flockhart, David

Patient attitudes toward genotyping in an urban women's health clinic

Obstetrics and Gynecology 2008 November; 112(5): 1023-1028

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Hayden, Erika Check

Accessible genomes move closer [news]

Nature 2008 October 23; 455(7216): 1014

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<http://www.nature.com> (link may be outdated)

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Harmon, Amy

New York Times 2008 October 20; p. A1, A17

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Nakashima, Ellen

Genome database will link genes, traits in public view [news]

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Science 2008 October 17; 322(5900): 509

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Scientists decode first Arab genome [news]

SciDev.net: Science and Development Network 2008 September 18; 2 p. [Online].

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When in doubt, spit it out; Want your DNA mapped? Saliva-collection parties gather all the evidence [news]

New York Times 2008 September 14; p. ST1, ST10



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Seller, Frances Stead

Family portraits: could you be Dick Cheney's cousin, too?

Washington Post 2008 July 20; p. B1, B5



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Me and my genome. What's it like to glimpse your genetic destiny in a personalised DNA readout?

New Scientist 2008 July 5-11; 199(2663): 36-39



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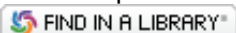


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Chan, Sarah

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EMBO reports 2008 July; 9 Suppl 1: S70-74



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From genetic privacy to open consent.

Nature Reviews. Genetics 2008 May; 9(5): 406-411



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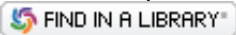


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Kristman, Vicki L.; Kreiger, Nancy

Information disclosure in population-based research involving genetics: a framework for the practice of ethics in epidemiology.

Annals of Epidemiology 2008 April; 18(4): 335-341



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Research ethics recommendations for whole-genome research: consensus statement.

PLoS Biology 2008 March 25; 6(3): e73



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Gene map becomes a luxury item

New York Times 2008 March 4; p. F1, F4



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Yesley, Michael S.

What's ELSI got to do with it? Bioethics and the Human Genome Project

New Genetics and Society 2008 March; 27(1): 1-6



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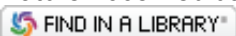


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Nature 2008 February 14; 451(7180): 763-765



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McGuire, Amy L.; Caulfield, Timothy; Cho, Mildred K.

Research ethics and the challenge of whole-genome sequencing

Nature Reviews. Genetics 2008 February; 9(2): 152-156

Supported by: NHGRI-funded publication; Grants R01HG04333 and 5P50HG3389



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Kaiser, Jocelyn

A plan to capture human diversity in 1000 genomes [news]

Science 2008 January 25; 319(5862): 395



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Researchers announce a step toward synthetic life [news]

New York Times 2008 January 25; p. A17



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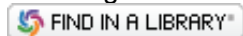


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Hunter, David J.; Khoury, Muin J.; Drazen, Jeffrey M.

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New England Journal of Medicine 2008 January 10; 358(2): 105-107



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THE HUMAN GENOME PROJECT IN COLLEGE CURRICULUM: ETHICAL ISSUES AND PRACTICAL STRATEGIES

Hanover, NH: Dartmouth College Press/University Press of New England, 2008. 188 p.

Call number: [QH445.2 .H92 2008](#)



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Personalized genomes go mainstream [news]

Nature 2007 November 1; 450(7166): 11



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Brenner, Steven E.

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Nature 2007 October 18; 449(7164): 783-784



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Wolinsky, Howard

The thousand-dollar genome. Genetic brinkmanship or personalized medicine?

EMBO Reports 2007 October; 8(10): 900-903



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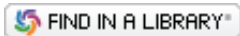


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Mayor, Susan

Genome sequence of one person is published for first time [news]

BMJ: British Medical Journal 2007 September 15; 335(7619): 530-531



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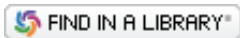
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Aldhous, Peter

Your own book of life. A raft of companies will soon be offering genome scans to paying customers.

However, our ability to say what genetic information means for health is highly limited, so will they just sow confusion?

New Scientist 2007 September 8-14; 195(2620): 8-11



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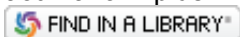


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Lumbreras, Blanca; Porta, Miquel; Hernández-Aguado, Ildfonso

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Journal of Epidemiology and Community Health 2007 September; 61(9): 755-756



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Knoppers, Bartha M.; Joly, Yann

Our social genome?

Trends in Biotechnology 2007 July; 25(7): 284-288



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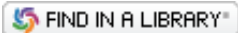
Article Document 39

Hoedemaekers, Rogeer; Gordijn, Bert; Pijnenburg, Martien

Solidarity and justice as guiding principles in genomic research

Bioethics 2007 July; 21(6): 342-350

Abstract: In genomic research the ideal standard of free, informed, prior and explicit consent is sometimes difficult to apply. This has raised concern that important genomic research will be restricted. Different consent procedures have therefore been proposed. This paper explicitly examines the question how, in genomic research, the principles of solidarity and justice can be used to justify forms of diminished individual control over personal data and bio-samples. After a discussion of the notions of solidarity and justice and how they can be related to health care and genomic research, we examine how and in which situations these notions can form a strong moral basis for demanding certain financial sacrifices. Then we examine when these principles can justify consent procedures which diverge from the ideal standard. Because much genomic research is not expected to lead to immediate (clinical) benefits we also discuss the question of whether we can be obliged to make any sacrifices for future (not yet existing) patients. We conclude with the formulation of a number of conditions that have to be met before autonomy sacrifices can be reasonably demanded in genomic research.



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Check, Erika

Celebrity genomes alarm researchers [news]

Nature 2007 May 24; 447(7143): 358-359



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Orchestrating a science 'event': the case of the Human Genome Project

New Genetics and Society 2007 April; 26(1): 65-83



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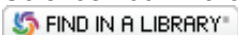


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Sequencers of a famous genome confront privacy issues [news]

Science 2007 March 30; 315(5820): 1780



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Lancet 2007 January 27 - February 2; 369(9558): 267



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Venter, J. Craig

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Munger, Kelly M.; Gill, Carol J.; Ormond, Kelly E.; Kirschner, Kristi L.

The next exclusion debate: assessing technology, ethics, and intellectual disability after the Human Genome Project

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Greif, Karen F.; Merz, Jon F.

Big science: the Human Genome Project and the public funding of science

In their: Current Controversies in the Biological Sciences: Case Studies of Policy Challenges from New Technologies. Cambridge, MA: MIT, 2007: 17-34

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McLean, Margaret R.

Religion, ethics, and the Human Genome Project

In: Eisen, Arri; Laderman, Gary, eds. Science, Religion, and Society: An Encyclopedia of History, Culture, and Controversy. Vol. 2. Armonk, NY: M.E. Sharpe, 2007: 787-794

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Caplan, Arthur L.

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In his: Smart Mice, Not-So-Smart People: An Interesting and Amusing Guide to Bioethics. Lanham, MD: Rowman & Littlefield, 2007: 119-138

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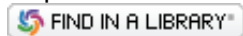
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Foster, Morris W.; Mulvihill, John J.; Sharp, Richard R.

Investments in cancer genomes: who benefits and who decides

American Journal of Public Health 2006 November; 96(11): 1960-1964

Abstract: The Cancer Genome Atlas—formerly the Human Cancer Genome Project—provides an opportunity for considering how social concerns about resource allocation are interrelated with practical decisions about specific research strategies—part of a continuing convergence between scientific and public evaluations of priorities for biomedical research funding. For example, the manner, order, and extent that The Cancer Genome Atlas selects tumor types and populations to be sampled will determine who benefits most from its findings. Those choices will be determined on the basis of both scientific and social values. By soliciting public involvement and conducting rigorous policy analysis in the design of large scientific projects such as The Cancer Genome Atlas, cancer researchers can help democratize the allocation of scientific resources and foster public confidence in biomedical research.



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Bostanci, Adam

Two drafts, one genome? Human diversity and human genome research

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Badagliacco, Joanna M.; Ruiz, Carey D.

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New Genetics and Society 2006 August; 25(2): 209-226



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Genome privacy [editorial]

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Tupasela, Aaro

Locating tissue collections in tissue economies -- deriving value from biomedical research

New Genetics and Society 2006 April; 25(1): 33-49



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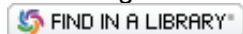


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Clayton, Ellen

Ethical concerns in HapMap project

Protecting Human Subjects 2006 Spring; (13): 9-11



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Racine, Eric; Gareau, Isabelle; Doucet, Hubert; Laudy, Danielle; Jobin, Guy; Schradeley-Desmond, Pamela

Hyped biomedical science or uncritical reporting? Press coverage of genomics (1992-2001) in Quebec

Social Science and Medicine 2006 March; 62(5): 1278-1290



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Greenhough, Beth

Decontextualised? Dissociated? Detached? Mapping the networks of bioinformatics exchange

Environment and Planning 2006 March; 38(3): 445-463



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Joly, Yann; Knoppers, Bartha M.

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Hjörleifsson, Stefán; Strand, Roger; Schei, Edvin

Health as a genetic planning project: enthusiasm and second thoughts among biomedical researchers and their research subjects

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Doring, Martin

A sequence of 'factishes': the media-metaphorical knowledge dynamics structuring the German press coverage of the human genome

New Genetics and Society 2005 December; 24(3): 317-336



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Gogorosi, Eleni

Untying the Gordian knot of creation: metaphors for the Human Genome Project in Greek newspapers

New Genetics and Society 2005 December; 24(3): 299-315



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Hellsten, lina

From sequencing to annotating: extending the metaphor of the book of life from genetics to genomics

New Genetics and Society 2005 December; 24(3): 283-297



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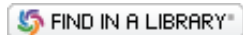


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Koski, Cheryl A.

The Human Genome Project: an examination of its challenge to the technological imperative

New Genetics and Society 2005 December; 24(3): 265-281



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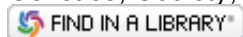


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Simm, Kadri

Benefit-sharing: an inquiry regarding the meaning and limits of the concept in human genetics research

Genetics, Society, and Policy 2005 August; 1(2): 29-40



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Diamond, Ian; Woodgate, Dawn

Genomics research in the UK -- the social science agenda

New Genetics and Society 2005 August; 24(2): 239-252



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Webster, Andrew

Social science and a post-genomic future: alternative readings of genomic agency

New Genetics and Society 2005 August; 24(2): 227-238



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Manasse, Henri R., Jr.

The other side of the human genome

American Journal of Health-System Pharmacy 2005 May 15; 62(10): 1080-1086



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Kirkman, Maggie

Public health and the challenge of genomics

Australian and New Zealand Journal of Public Health 2005 April; 29(2): 163-165



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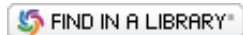


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Nicotine addiction through a neurogenomic prism: ethics, public health, and smoking

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The Harvard case of Xu Xiping: exploitation of the people, scientific advance, or genetic theft?

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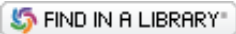


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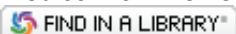


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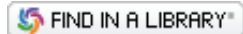


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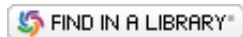


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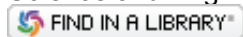


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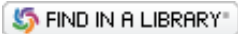


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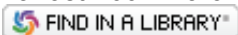


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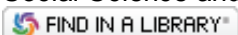


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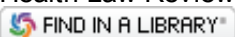


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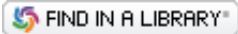


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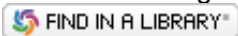


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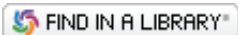


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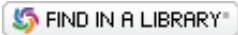


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DNA: The Human Race (2003)

Films for the Humanities & Sciences

Abstract: "In 1990, a massive enterprise was launched to decipher the ultimate instruction manual. The Human Genome Project soon turned into a race and a feud. This program tracks the tumultuous progress of the endeavor, detailing the scientific innovations that led to its completion as well as its political and economic impact. Exceptional graphics bring home the daunting task of sequencing the human genome. Among those who discuss the project are initial rivals Francis Collins and J. Craig Venter; Dr. John Sulston; Sir Alec Jeffreys, the discoverer of DNA fingerprinting; Nobel Laureates Fred Sanger and Jim Watson; and former President Bill Clinton." [description from cassette box] Series Description: "Fifty years ago, two unknown scientists ran into an English pub shouting that they had found the secret of life. Jim Watson and Francis Crick were not exaggerating. Narrated by Jeff Goldblum, this series looks back on the achievements that launched a new era in biology and human life itself. Along with an incredible array of renowned scientists, including five Noble Laureates, these programs use beautifully realized animations and reconstructions of key experiments to reveal the molecular basis of life in a way never seen before." [description taken from back cover]

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Foster, Morris W.

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Arnason, Einar; Wells, Frank

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Kerzin-Storarr, Lauren

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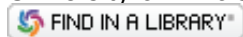


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Pinto, Ashok M.

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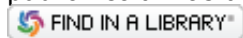
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Brodwin, Paul

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Althanasiou, Tom; Darnovsky, Marcy

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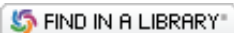


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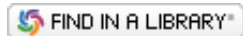


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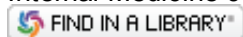


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Wolpe, Paul Root

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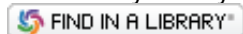


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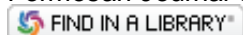


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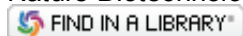


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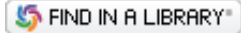


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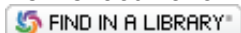


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Abstract: "Does it amaze you that yeast is your very close relative? That you possess roughly the same number of genes as a mouse? That you are 99.9% genetically identical to every other human? ABC Nightline correspondent Robert Krulwich lends a lighthearted touch to genetic science in this provocative two-hour NOVA special that takes you inside the amazing, complex and contentious race to decode the human genome. The Human Genome Project was born in 1990, when an international consortium of labs set out to sequence all 3 billion letters of our DNA, predicting they'd finish by 2005. Halfway though their schedule, controversial scientist and entrepreneur J. Craig Venter threw the genome world into turmoil when he announced his for-profit company Celera could finish the job in just two years. Francis Collins, leader of the publically-funded effort, and MIT's Eric Lander were among the scientists who answered Venter's challenge. The result made history and laid the foundation for a remarkable future. Armed with this powerful information, medical pioneers are in the midst of astonishing breakthroughs that will change medicine as we know it. Will you get cancer, arthritis, or Alzheimer's? The answer lies in your genetic code-but the question is: Do you want to know? And will these new discoveries eventually lead to cures?" [Description from NOVA cassette box] "In June 2000, two fiercely competitive teams of scientists made the joint announcement that their labs had achieved one of the greatest prizes in history: the decoding of the human genome. NOVA tells the story of the genome triumph and its profound implications for medicine and human health in this special, hosted by Robert Krulwich, ABC "Nightline" correspondent." [Description taken from TV Guide listing.] Program aired on April 17, 2001. Footage includes interviews with Dr. Francis Collins, director of the National Center for Human Genome Research; Dr. Craig Venter, head of its rival, the private Celera Genomics; and the Whitehead Institute's Dr. Eric Lander, one of the leaders of the Human Genome Project. Human Genome Project; Celera Genomics; DeCode; Iceland; tay sachs; cystic fibrosis; breast cancer

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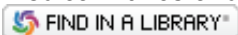


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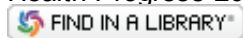


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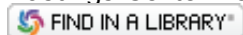


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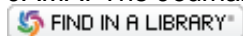


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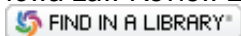


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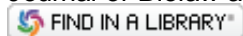


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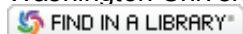


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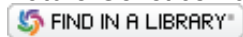
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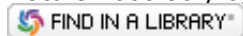


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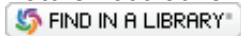


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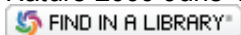
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* Article Document 240

Debates Over Credit for the Annotation of Genomes [editorial]

Nature 2000 June 15; 405(6788): 719



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A/V Document 241

Charlie Rose Show: Mapping the Human Genome, Parts I-V (2000)

1-800-ALL-NEWS, LLC

Abstract: Part I, June 19, 2000, Show No. 2707. "Craig Venter Predicts Celera Won't Become Drug Company." Participants: Dr. J. Craig Venter, President, Chief Science Officer, Celera Genomics; Marshall Peterson, Vice-President, Celera Genomics; Dr. Hamilton Smith, Nobel Laureate; and Dr. Francis Collins, Director, National Human Genome Research Institute Part II, June 20, 2000, Show No. 2708. "NIH Biologist Says Medicine Needs a 'Genomic Attitude'." Participants: Dr. Francis Collins, Director, National Human Genome Research Institute, NIH; Dr. Judy Crabtree, Research Fellow, NIH; Dr. Steven Lipkin, Human Genome Research Institute; Dr. David Duggan, Research Fellow, NIH; Dr. Olli-P. Kallioniemi, Human Genome Research Institute Part III, June 21, 2000, Show No. 2709. "Harold Varmus Says Genome Is More Than Gene Therapy" and "James Watson Discusses Public, Private Genome Projects." Participants: Dr. James Watson, Nobel Laureate; Dr. Harold Varmus, President, Memorial Sloan-Kettering Cancer Center and Former Director of the National Institutes of Health; Dr. Arnold Levine, President, Rockefeller University; Dr. Savio Woo, President American Society of Gene Therapy Part IV, June 22, 2000, Show No. 2710. "Reporter Lists His Heroes from the Human Genome Project" (Nicholas Wade) and "Reporter Says Genomics Race Fueled by Publishing Fear (Richard Preston" and "Biotech Businessmen Call Genome Project 'Conceptual'" (Viren Mehta and William Haseltine). Participants: Nicholas Wade, Science Writer, The New York Times; Richard Preston, The New Yorker; Dr. Viren Mehta, Director, Mehta Partners Global Healthcare Investors; Dr. William Haseltine, CEO, Human Genome Sciences, Inc. Part V, June 23, 2000, Show No. 2711. "Ethics and the Implications of the Human Genome Project." Participants: Dr. J. Craig Venter, President, Chief Science Officer, Celera Genomics; Dr. Hamilton Smith, Nobel Laureate; Dr. Francis Collins, Director, Human Genome Research Institute, NIH; Dr. Harold Varmus, President, Memorial Sloan-Kettering Cancer Center and Former Director of the National Institutes of Health; Dr. Arnold Levine, President, Rockefeller University; Dr. James Watson, Nobel Laureate; Nicholas Wade, Science Writer, New York Times; Dr. William Haseltine, CEO, Human Genome Sciences; Dr. Arthur Caplan, Director, Center for Bioethics, University of Pennsylvania



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Pelias, Mary Z.; Markward, Nathan J.

The Human Genome Project and public perception: truth and consequences

Emory Law Journal 2000 Summer; 49(3): 837-858



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Elsas, Louis J.

Medical genetics: present and future benefits

Emory Law Journal 2000 Summer; 49(3): 801-822



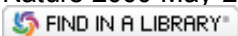
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Ethical Divide on US Genome Project [news brief]

Nature 2000 May 25; 405(6785): 388



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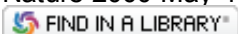


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Triendl, Robert

Japan Calls For Open Access to Human Genome Data. [News].

Nature 2000 May 18; 405(6784): 265



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* **Article** Document 246

Mukherjee, Siddhartha

Wrong Map: Why Public Science Can't Really Be Public [Celera and the Human Genome Project]

New Republic 2000 May 8; 222(19): 14-15



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* **Article** Document 247

Epstein, Charles J.

Some Ethical Implications of The Human Genome Project

Genetics in Medicine 2000 May-June; 2(3): 193-197



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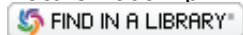


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Smaglik, Paul

Genetic Diversity Project Fights For Its Life . . . As Companies Are Urged to Share Benefits [news]

Nature 2000 April 27; 404(6781): 912



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McConkey, Edwin H.; Fouts, Roger; Goodman, Morris; Nelson, David; Penny, David; Ruvolo, Maryellen ; Sikela, James; Stewart, Caro-Beth; Varki, Ajit; Wise, Steven

Proposal for a Human Genome Evolution Project [editorial]

Molecular Phylogenetics and Evolution 2000 April; 15(1): 1-4



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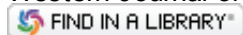


* **News** Document 250

Josefson, Deborah

Biotechnology Company Claims to Have 97% of Human Genes on Its Database [news]

Western Journal of Medicine 2000 April; 172(4): 228



<http://www.ncbi.nlm.nih.gov/pmc/journals/183/> (link may be outdated)



* **Article** Document 251

Collins, Francis

In the Crossfire: Collins on Genomes, Patents, and "Rivalry". [Interview by Eliot Marshall, Elizabeth Pennisi, and Leslie Roberts].

Science 2000 March 31; 287(5462): 2396-2398



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Alberts, Bruce; Klug, Aaron

"The Human Genome Itself Must Be Freely Available to All Humankind" [statement of Bruce Alberts, president of the U.S. National Academy of Sciences, and Sir Aaron Klug, president of the Royal Society of London]

Nature 2000 March 23; 404(6776): 325



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Butler, Declan

U. S./U. K. Statement on Genome Data Prompts Debate on "Free Access" [news]

Nature 2000 March 23; 404(6776): 324-325



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* Article Document 254

Rules of Genome Access [editorial]

Nature 2000 March 23; 404(6776): 317



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Marshall, Eliot

Talks of Public-Private Deal End in Acrimony [news]

Science 2000 March 10; 287(5459): 1723, 1725



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Jin, Janice

An evaluation of the Ethical, Legal and Social Implications program of the U. S. Human Genome Project

Princeton Journal of Bioethics 2000 Spring; 3(1): 35-50



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* Unpublished Document 257

National Human Genome Research Institute [NHGRI]. National Advisory Council for Human Genome Research (NACHGR) / Department of Energy [DOE]. Biological and Environmental Research Advisory Committee (BERAC). ELSI Research Planning and Evaluation Group [ERPEG]

A Review and Analysis of the Ethical, Legal, and Social Implications (ELSI) Research Programs at the National Institutes of Health and the Department of Energy

Unpublished document: February 10, 2000, 36 p., i-iv, appendices.



* Article Document 258

SoRelle, Ruth

Who owns your DNA? Who will own it?

Circulation 2000 February 8; 101(5): e67-e68



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Butler, Declan; Smaglik, Paul

Celera Genome Licensing Terms Spark Concerns Over "Monopoly" [News]

Nature 2000 January 20; 403(6767): 231



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Private vs Public Genomics? [editorial]

Nature 2000 January 13; 403(6766): 117



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Greely, Henry T.

Iceland's plan for genomics research: facts and implications

Jurimetrics 2000 Winter; 40: 153-191



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A/V Document 262

The Code

Aquarius Productions

Abstract: "The fascinating interplay between heredity and environment in determining the health of an individual begins at conception. With the completion of the Human Genome Project, research into the genetic links to disease and other aspects of the 'human condition' is receiving a great deal of attention." [from Aquarius Productions catalog description]

<http://www.aquariusproductions.com> (link may be outdated)



Book Document 263

Macer, Darryl R.J., ed.

ETHICAL CHALLENGES AS WE APPROACH THE END OF THE HUMAN GENOME PROJECT

Christchurch, New Zealand: Eubios Ethics Institute, 2000. 123 p.

Call number: [QH332 .E67 2000](#)



* **Book** Document 264

Vicini, Andrea

THE ETHICS OF GENETIC TECHNOLOGY: KNOWLEDGE, THE COMMON GOOD, AND HEALING: THE CASE OF THE HUMAN GENOME PROJECT

Ann Arbor, MI: UMI/ProQuest, 2000. 399 p.

Call number: [QH442 .V5 2000](#) FIND IN A LIBRARY®

Document 265

Deutsche Forschungsgemeinschaft. Senatskommission für Grundsatzfragen der Genforschung = Senate Commission on Genetic Research

HUMANGENOMFORSCHUNG: PERSPEKTIVEN UND KONSEQUENZEN = GENOME RESEARCH: PERSPECTIVES AND CONSEQUENCES

Weinheim: Wiley-VCH [and] Bonn: Deutsche Forschungsgemeinschaft, 2000. 137 p.



Book Document 266

Zilinskas, Raymond A. and Balint, Peter J., eds.

THE HUMAN GENOME PROJECT AND MINORITY COMMUNITIES: ETHICAL, SOCIAL, AND POLITICAL DILEMMAS

Westport, CT: Praeger, 2000. 144 p.

Call number: [QH445.2 .H88 2001](#) FIND IN A LIBRARY®



Book Document 267

Sloan, Phillip R., ed.

CONTROLLING OUR DESTINIES: HISTORICAL, PHILOSOPHICAL, ETHICAL, AND THEOLOGICAL PERSPECTIVES ON THE HUMAN GENOME PROJECT

Notre Dame, IN: University of Notre Dame Press, 2000. 535 p.

Call number: [QH445.2 .C65 2000](#) FIND IN A LIBRARY®



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Piper, Tina

The collusion of law and science in the piracy of human genes

Dalhousie Journal of Legal Studies 2000; 9: 237-277

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Greely, Henry T.

Human Genome Diversity Project.

In: Murray, Thomas H.; Mehlman, Maxwell J., eds. Encyclopedia of Ethical, Legal, and Policy Issues in Biotechnology. 2 vols. New York: John Wiley & Sons; 2000: 552-566.

Call number: [TP248.16 .E539 2000 v.2](#)



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Hanna, Kathi E.

Federal policy making for biotechnology, executive branch, National Human Genome Research Institute.

In: Murray, Thomas H.; Mehlman, Maxwell J., eds. Encyclopedia of Ethical, Legal, and Policy Issues in

Biotechnology. 2 vols. New York: John Wiley & Sons; 2000: 249-257.
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Chapter Document 271

Juengst, Eric T.

Concepts of disease after The Human Genome Project.

In: Wear, Stephen; Bono, James J.; Logue, Gerald; McEvoy, Adrienne, eds. Ethical Issues in Health Care on the Frontiers of the Twenty-First Century. Boston, MA: Kluwer Academic Publishers; 2000: 127-154.

Call number: [R724 .E7879 2000](#)



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Bono, James J.

The human genome, difference, and disease: nature, culture, and new narratives for medicine's future.

In: Wear, Stephen; Bono, James J.; Logue, Gerald; McEvoy, Adrienne, eds. Ethical Issues in Health Care on the Frontiers of the Twenty-First Century. Boston, MA: Kluwer Academic Publishers; 2000: 115-126.

Call number: [R724 .E7879 2000](#)



Chapter Document 273

McCormick, Richard A.

Moral theology and the Genome Project.

In: Sloan, Phillip R., ed. Controlling Our Destinies: Historical, Philosophical, Ethical, and Theological Perspectives on the Human Genome Project. Notre Dame, IN: University of Notre Dame Press; 2000: 417-427.

Call number: [QH445.2 .C65 2000](#)



Chapter Document 274

Dreger, Alice Domurat

Metaphors of morality in the Human Genome Project.

In: Sloan, Phillip R., ed. Controlling Our Destinies: Historical, Philosophical, Ethical, and Theological Perspectives on the Human Genome Project. Notre Dame, IN: University of Notre Dame Press; 2000: 155-184.

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Chapter Document 275

Beyleveld, Deryck; Brownswork, Roger

Human dignity, human rights, and the human genome.

In: Rendtorff, Jacob Dahl; Kemp, Peter, eds. Basic Ethical Principles in European Bioethics and Biolaw. Volume II: Partners' Research. Copenhagen: Centre for Ethics and Law; 2000: 15-44.

Call number: [KJC6227 .R46 2000 v.2](#)



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Drell, Daniel W.

Informing federal policy on biotechnology: executive branch, Department of Energy.

In: Murray, Thomas H.; Mehlman, Maxwell J., eds. Encyclopedia of Ethical, Legal, and Policy Issues in Biotechnology. 2 vols. New York: John Wiley & Sons; 2000: 697-703.

Call number: [TP248.16 .E539 2000 v.2](#)



A/V Document 277

The Human Genome Education Model [HuGEM Project] (1996)

Georgetown University Child Development Center

Abstract: The HuGEM Project is a collaboration between the Georgetown University Child Development Center, a division of the Department of Pediatrics, Georgetown University Medical Center, and the Alliance of Genetic Support Groups. Presenters are Dr. E. Virginia Lapham and Dr. Francis S. Collins. This set of tapes is accompanied by a 68-page manual authored by E. Virginia Lapham, et al. Part I: The HuGEM Project: Overview of the Human Genome Project and Its Ethical, Legal and Social Issues, 19 minutes. Part II: The HuGEM Project: Opportunities and Challenges of the Human Genome Project, 24 minutes. Part III: The HuGEM Project: Issues of Genetic Privacy and Discrimination, 45 minutes (revised). Part IV: The HuGEM Project: Genetic Testing Across the Lifespan, 30 minutes. Part V: The HuGEM Project: Working Together to Improve Genetic Services, 28 minutes.



Document 278

The Book of Man (1994)

Abstract: The program considers the origins and development of the Human Genome Project.



Document 279

The Human Genome Project (1991)

National Center for Human Genome Research

Abstract: Dr. James Watson, director of the Human Genome Project (at that time) opens the film, noting that mapping 100 trillion cells is a vast undertaking. Three scientists discuss different genetic diseases: David Houseman of MIT, Wilm's tumor; Nancy Wexler, Huntington's disease; and Robert Murray of Howard University, Sickle cell anemia.



Document 280

The Human Genome (1990)

Films for the Humanities & Sciences

Abstract: The film opens with identical twins whose lives are remarkably the same even though they grew up apart. Other genetic similarities are presented and cystic fibrosis is discussed as the most common of the inherited diseases. The human genome mapping plan is illustrated and explained.



Document 281

Decoding the Book of Life (1989)

Coronet Film & Video

Abstract: The film provides a brief history of eugenics and the development of molecular biology, going on to describe the beginnings of the human genome project in 1985. It traces the project's development, reports on the Department of Energy's role, shows technologies used to study and map the genome, and notes criticisms and concerns which have been expressed about genome mapping.

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