mind•full: a brainsnack for future leaders with ethical appetites

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computers & human genetics

Today's revolutions in computer science and biotechnology are creating a world of new capabilities in the field of human genetics and raising key questions as to how society should integrate these new technologies together. Finding faster ways to sequence DNA, through the Human Genome Project (HGP) and other efforts, has led to new computer hardware and software that increasingly allows researchers to explore the complexity of genetics with unmatched speed, quality, and detail. This will have a tremendous impact on the future of medicine.

Informatics tools, supercomputers, chip technology, publicly accessible databases, imaging techniques, and advanced software and hardware are now crucial to genetics research. This interdisciplinary approach involves a number of fields outside biology, such as physics, engineering, chemistry, and mathematics. In addition, increasing reliance on the Internet and the World Wide Web enables exciting new international collaborative efforts and increased sharing of information around the globe.

The introduction of new technologies in genetic research raises many ethical, legal, and social issues. The dizzying rate at which genetic information is becoming available today outpaces society's ability to safeguard against potential misuses. The profound impact these capabilities will have on our personal and collective lives has yet to be explored fully as policy makers and legislators continue to struggle to keep up with these new developments. As much more information becomes available about each individual's genetic makeup, society can be certain that many more ethical issues are awaiting us in the not-too-distant future.

The mission of Student Pugwash USA is to promote the socially responsible application of science and technology in the 21st century. As a student organization, Student Pugwash USA encourages young people to examine the ethical, social, and global implications of science and technology, and to make these concerns a guiding focus of their academic and professional endeavors.

The **mind•full** series encourages readers to explore crucial ethical dilemmas associated with the application of science and technology.

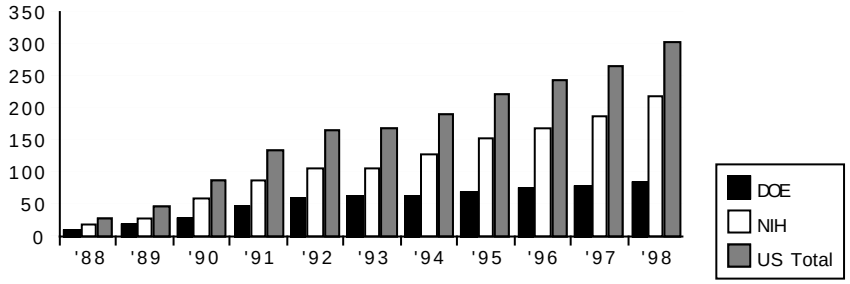
STUDENT PUGWASH USA

go figure!

The human genome is comprised of three billion base pairs. According to the National Institutes of Health, if printed out, the human genome would fill 1,000 one-thousand page telephone books. The process of mapping, sequencing, and compiling this information presents an obstacle that can be managed only by sophisticated computational techniques. Using computers to decipher, manage, and organize this information means that the time it takes to find disease genes can be reduced from years to days.

In the United States, the Human Genome Project is an extensive research effort involving the National Institutes of Health, the Department of Energy, and researchers across the country. In addition, according to the Human Genome Management Information System, at least 18 countries have human genome projects and over 1,000 researchers from 50 countries are members of the Human Genome Organization (HUGO), which coordinates international collaboration in the human genome project.

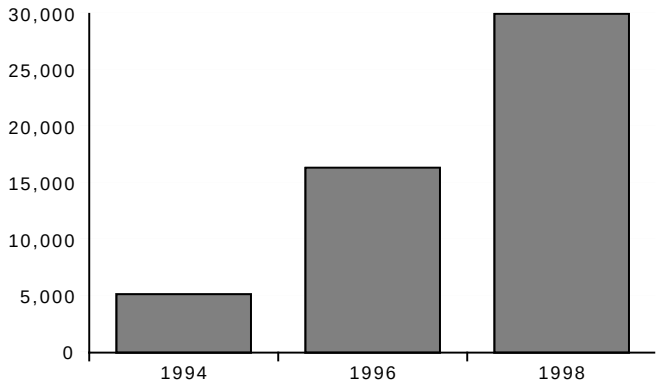
united states human genome project funding (in millions of dollars)



	DOE	NIH	US Total
1988	10.7	17.2	27.9
1989	18.5	28.2	46.7
1990	27.2	59.5	86.7
1991	47.4	87.4	134.8
1992	59.4	104.8	164.2
1993	63	106.1	169.1
1994	63.3	127	190.3
1995	68.7	153.8	222.5
1996	73.9	169.3	243.2
1997	77.9	188.9	266.8
1998	85.5	217.7	303.2

Source: "Human Genome Project: Frequently Asked Questions," Human Genome Management Information System, Oak Ridge National Laboratory, www.ornl.gov/TechResources/Human_Genome/faq/faqs1.html. August 1998.

the gene scene



number of mapped genes

1994	5,131
1996	16,354
1998	30,011

Source: Office of Communications, National Human Genome Research Institute, National Institutes of Health, phone conversation, 8/12/98.

in control or out of it?

Researchers now estimate that, with the aid of computers, the publicly funded Human Genome Project will be completed by 2003, sooner than previously anticipated. This new timetable is driven in part by competition with private companies. In early 1998, The Institute for Genome Research (TIGR) and Perkin-Elmer Corporation announced their joint effort to sequence the entire human genome by the end of 2001. This rekindled public discussion over the impact of private companies, driven by a proprietary and profit motives, venturing into what was intended by governments to be a public effort. Supporters of private research argue that an economically competitive environment propels biomedical research, and that this has significant positive impact on society. Some warn, however, that the sequence generated by private companies might be less accurate and complete than that of the HGP. In addition, extensive legal battles might erupt over the private companies' right to patent and profit from discovered genes. Such discussions raise questions about whether anyone should "own" parts of the human genome.

International and national efforts are underway to help society determine how to integrate these new technologies in responsible ways. In 1997, the United Nations Educational, Scientific and Cultural Organization (UNESCO) unanimously adopted a "Universal Declaration on the Human Genome and Human Rights." This unique declaration claims the human genome is "the heritage of humanity." It outlines guidelines that balance individual freedom and the exercise of scientific activity. In the US, the National Human Genome Research Institute's Ethical, Legal and Social Implications (ELSI) program explores privacy and fairness in the use and interpretation of genetic information, clinical integration of new genetic technologies, issues surrounding genetics research, and related public and professional education.

There are a number of committees, task forces, and working groups that also are addressing the ethical implications of genetic research, including the US National Bioethics Advisory Commission, which advises the president. However, at the increasing rate with which genetic information is becoming available, it is very difficult for policy makers to ensure its appropriate use and to address issues such as possible genetic discrimination, privacy and confidentiality, and access to health care and insurance.

nerds' words

biotechnology—a set of biological techniques developed through basic research and now applied to research and product development.

gene mapping—determination of the relative position of genes [in] DNA [. . .] and of the distance between them.

genome—all the genetic material in the chromosome[s] of a particular organism; its size is generally given as [a] total number of base pairs.

human genome project*—begun in 1990, the US HGP is a 15-year effort coordinated by the US Department of Energy and the National Institutes of Health to identify all the estimated 80,000 genes in human DNA, determine the sequences of the 3 billion chemical bases that make up human DNA, store this information in databases, and develop tools for data analysis.

informatics—the study of the application of computer and statistical techniques to the management of information. In genome [research], informatics includes the development of methods to search databases quickly, to analyze DNA sequence information, and to predict protein sequence and structure from DNA sequence data.

sequencing—determination of the order of nucleotides [. . .] in DNA.

* Definition taken from "Human Genome Project: Frequently Asked Questions," Human Genome Management Information System, Oak Ridge National Laboratory, www.ornl.gov/TechResources/Human_Genome/faq/faqs1.html.
All other definitions taken from *DOE Human Genome Program: Primer on Molecular Genetics*. United States Department of Energy, Office of Energy Research, Office of Health and Environmental Research, Washington, DC: June 1992.
Changes in brackets provided by Dr. Eric Green, NHGRI.

Biochips Ahoy!

Researchers are developing DNA chips or "biochips," an exciting new technology that holds great promise in terms of disease diagnostics and improved medical treatment. A biochip contains up to 100,000 short pieces of DNA on a piece of glass the size of a thumbnail. Much like a regular computer chip, it reads and processes thousands of biochemical reactions in a mere few seconds using a combination of fluorescent and laser techniques that reveal an image that a computer then reads. Doing what previously took a matter of days, the DNA chip makes it possible to "speed read" through DNA to find a genetic variation within a matter of minutes. The implications are tremendous. With only a drop of blood, a researcher could be able to identify mutated genes that have the potential to lead to diseases or rapidly confirm a diagnosis. The time this saves could make all the difference in a life-saving treatment. Already, chip technology correctly identified breast cancer gene mutations in 14 out of 15 patients. Companies such as Motorola, Affymetrix, and Packard recognize the value of the DNA chip and are placing significant resources into mass-producing and refining the technology.

data, bases, and you?

Electronic databases are increasingly important in genetics research as they provide the central means to share information about the growing human genome map. Databases recognize patterns that make it easier to identify disease genes more accurately and faster. With 4,000 known inherited diseases, this is a key source of information for researchers and doctors. For example, the Online Mendelian Inheritance in Man database lists thousands of sites of genetic mutations and hundreds of medical conditions. In addition, the Human Genome Project research is available worldwide through the International Nucleotide Sequence Database Collaboration, which is comprised of the DNA DataBank of Japan, the European Molecular Biology Laboratory, and the GenBank at the National Center for Biotechnology Information at the US National Institutes of Health.

nature's computer

Nature's own computer, the living cell, is by far more efficient at storing and processing information than the most sophisticated computers. The living cell is able to compress huge amounts of code into the compact space of its nucleus, using less energy and space than a computer. Effectively outperforming modern-day computers by orders of magnitude, the cellular method of "programming" is also more sophisticated. While computer programs today are written sequentially, or "linearly," in much the same way a programmer thinks, the cell concurrently reads and processes multiple pieces of DNA code to perform simultaneous or "parallel" tasks. A lab experiment in 1994 proved DNA could be used to encode and solve a particular type of computer science problem for which man-made programs had proven inefficient or unsuccessful. Computer scientists and biologists alike are interested in understanding how cells use DNA to program functions so effectively, as they look towards potential applications for conventional computers. AT&T, IBM, and other companies already have recognized the value of participating in the exploration of this novel field. Who knows? Instead of rooms full of supercomputers, tomorrow's computers may be found in petri dishes full of cells.

(anything but a) conclusion

The computer has become critical to the future of genetics research. While it has allowed researchers to handle large amounts of information efficiently, huge questions still remain over what we choose to do with the knowledge and capabilities made available by this technology. The increasingly rapid pace of discovery, made possible by more advanced computers and other tools, draws into sharp focus the need for societal guidance to safeguard against misuse and abuse of this information. On a more fundamental level, some worry that being able to define each individual by their genetic blueprint may change the way we view our humanity. Others say, however, that going into this unknown area may help us ensure a better life for some people and is therefore worth any such risks.

How do **you** answer the **tough questions**

Moore's law says that the speed of computers doubles every eighteen months. Do you think these changes in the computer industry pose special challenges and opportunities for the field of genetics? If they contribute to an increased pace of discovery and technical capability, what steps do you think we should take to ensure policy makers are able to keep up with the social and legislative needs that arise?

As the utility of mathematical and computational approaches in biology ever increases, how important do you think it is that future biological scientists have stronger groundings in math and computer science? Do you think our secondary and post-secondary educational systems are up to the challenge? Because the potential social impact of these fields is so profound, do you think educators have a special responsibility to address ethical issues in the curriculum?

New genetic technologies will increase our ability to determine our genetic predisposition to certain diseases. This raises quality of life questions. If you were to find out that you carry a gene for breast cancer, which may be passed on to your offspring, would that stop you from having a child? Would you decide to have an expensive radical preventive surgery even though it is not certain you would develop cancer? What kind of information would you need from your physician in order to be able to make these types of decisions?

Do you think a research institution in a developing country should spend its money for computer systems that allow it to access international databases, or do you think its funds would be better spent on basic research relating to local health concerns such as malnutrition or malaria? What are the trade-offs and benefits of either approach? Do you think the US is spending too much money on the Human Genome Project and ignoring other, more basic needs?

Most of the public databases, like the US GenBank, provide access free of charge. However, private companies also maintain online databases and sometimes charge a significant fee for their use. For example, Incyte Pharmaceuticals, based in Palo Alto, California, charges nine of the ten largest pharmaceutical companies in the world millions of dollars per year to use their database and also charges academic and governmental institutions for this use. What impact do you think private databases will have on future research? What benefits do you think will result from private initiatives?

Do you think the Human Genome Project's decision to set aside a portion of its funds to consider the ethical, legal, and social implications of its work should serve as a model for other research initiatives? What are the benefits of this approach? Do you think such research is a legitimate part of "science" or do you think it belongs in the realm of social science?

Do you think a private company has the right to patent any or all of the human genome? Who should decide? Should there be any limit to how much private companies can profit on technologies derived from information made available through public efforts like the HGP? Why or why not?

Do you think the public has enough knowledge about the impact of recent developments in computers and genetics? Who is responsible for providing this education—schools, the media, individuals, corporations, or the medical community? Do you think the scientists bear a special responsibility in conveying the pros and cons of new technologies to the public? How do you think the public should convey to its leaders what boundaries it would place on such research?

The US military already requires its soldiers to provide DNA samples for identification purposes. In the not-too-distant future it may be possible for you to be identified by a "DNA card" rather than a social security number. What do you think would be the benefits of this? What would be the drawbacks? Who would you trust to safeguard this information? What effects, if any, do you think this could have on healthcare, discrimination in the workplace, etc.?

Some worry that this new amount of genetic information may be used for eugenics—attempting to "improve" a population through selective breeding. Do you see this as a danger? Who should decide what is a "good" gene versus a "bad" gene? In a world where some people choose abortions based on a child's gender, how do you think we will be able to handle vast amounts of knowledge about genetic predispositions to certain diseases or even, say, baldness?

bound data

• *Access to the Genome: The Challenge of Equality*, Maxwell J. Mehlman and Jeffrey R. Botkin—this book is an exploration of the potential harms of genetic research and technology, focusing on the "genetic haves and have nots." Washington, DC: Georgetown University Press, 1998.
• *Biotechnology Unzipped: Promises and Realities*, Eric Grace—a chronological overview of the field of biotechnology. A very friendly read, kind of funny. Washington, DC: National Academy Press, 1997.
• *Codes of Codes: Scientific and Social Issues in the Human Genome Project*, Daniel J. Kelves and Leroy Hood (editors)—an ethical exploration of the Human Genome Project. Cambridge, MA: Harvard University Press, 1992.
• *Evaluating Human Genetic Diversity*—National Research Council, Washington, DC: National Academy Press, 1998.
• "Evolution Revolution," Charles Platt—a past, present, and future account of the genetic era; a very interesting article. *Wired Magazine*, Volume 5, Number 1, January 1997, p. 158.

check it out !

• "Exploring Human Genetics," Constance Lassiter and Susan Higman—a very good introduction to the field of genetics (our personal favorite). *Mind•full: a brainsnack for future leaders with ethical appetites.* Volume 2, Number 7, Student Pugwash USA, October 1997. You can download this at www.spusa.org/pugwash/.
• "Funders Reassure Genome Sequencers"—the "race" between the international Human Genome Project and the private companies. *Science Magazine*, Volume 280, Number 5367, May 22, 1998, p. 1185.
• *Harnessing the Gene and Remaking the World: The Biotech Century*, Jeremy Rifkin—an easy read for those who like predictions. New York: Penguin Putnam Inc, 1998.
• *Mapping Our Genes: The Genome Project and the Future of Medicine*, Lois Wingerson—a very good account of the scientific world of genetics. New York: Plume Printing, 1990.
• "Silicon chips scan thousands of genes at once, speeding genetic studies," a December 9, 1996 press release from Stanford University Medical Center. On the Web at http://www-med.stanford.edu/center/communications/Pressrel/December96/.
• *Towards the 21st Century: Incorporating Genetics into Primary Health Care*, Nancy Touchette, Neil A. Holtzman, Jessica G. Davis, Suzanne Feetham—exploring the impact of genetics in medicine. New York: Cold Harbor Laboratory Press, 1997.
• "Where Computers and Biology Meet: Making a DNA Chip," *Nanothinc/New York Times*, April 8, 1997.
• Universal Declaration on the Human Genome and Human Rights—proposed safeguards against genetic discrimination and patenting. On the Web at http://www.unesco.org/opi/29gencon/egenkit.htm.

scan the big screen

• *Human Genome Project*—(video) "a journey through the genetic makeup of a cell and steps to finding a gene." This 1996 video is available free-of-charge from the National Human Genome Research Institute. To order, contact: Office of Communications, National Human Genome Research Institute by fax 301-402-2218 or call 301-402-0911.
• *Blade Runner*—In this film, Harrison Ford hunts for "replicants" (genetically engineered robots) with human appearance and superhuman ability that were built to explore and build other worlds in space (very Pugwashy), 1982.
• *Ada's Conception*—In this movie a computer genius uses her genetic information as a means of communication to bring someone from the past to the present, 1997.

cyberspace

top picks

• Human Genome News (excellent Web site if you have questions concerning any aspect of the HGP, this site links to a number of organizations and institutions where other genome projects are taking place)—http://www.ornl.gov/hgmis

• Access Excellence About Biotech—a very comprehensive site explaining the expectations of the Human Genome Project—http://www.gene.com/ae/AB

best of the rest

• Affymetrix (a biotechnology company is responsible for the production of the DNA chip)—http://www.affymetrix.com
• Celera Genomics Corporation (a new company formed by Perkin-Elmer and Dr. J. Craig Venter of The Institute for Genomic Research)—http://www.celera.com
• Department of Energy Human Genome Program—http://www.er.doe.gov/production/ober/hug_top.html
• Ethical, Legal, and Social Implications (ELSI) program—http://www.nhgri.nih.gov/ELSI/ and http://www.ornl.gov/TechResources/Human_Genome/ersource/elsi.html
• Hewlett Packard Chemical Analysis Products (computer company that teamed with Affymetrix to produce the GeneArray scanner used to read the DNA chip)—http://chem.external.hp.com/cag/products/genearray.html
• Human Genome Organization (HUGO)—an international organization that promotes world wide collaboration on the HGP—http://hugo.gdb.org
• The Genome Database at Johns Hopkins University School of Medicine—http://www.gdb.org
• National Human Genome Research Institute, Genome Technology Branch—http://www.nhgri.nih.gov/DIR/GTB
• National Center for Biotechnology Information (links to GenBank and sample DNA data)—http://www.ncbi.nlm.nih.gov
• National Biomedical Computation Resource at the San Diego Supercomputer Center—http://www.sdsc.edu/nbcr
• Nature Genetics Magazine—article demonstrates the technique behind the DNA chip—http://www.genetics.nature.com

This **mind•full** was written by Constance Lassiter and Julia Fu. Constance was formerly Student Pugwash USA's Pledge/New Careers Coordinator and is now doing an academic research apprenticeship at the Howard University Cancer Center. Julia is a biology and government dual degree student at the University of Maryland, College Park and a chapter representative on Student Pugwash USA's board of directors. Special thanks to Dr. Eric Green, Chief, Genome Technology Branch, National Human Genome Research Institute, National Institutes of Health and Norman Furlong, staff engineer, Sun Microsystems, for their comments. Any errors are the responsibility of Student Pugwash USA.

but wait, there's more!

• **mind•full: a brainsnack for future leaders with ethical appetites**. Volume one available, includes: international weapons trade; emerging infectious diseases; access and the Internet; public's role in science; future of nuclear weapons; water quality and availability; war and disease; renewable energy. Volume two issues available: pugwash conferences; exploring human genetics; science, technology, & culture; communications technologies; beyond nuclear weapons; nuclear energy.

• **Jobs You Can Live With: Working at the Crossroads of Science, Technology, and Society**. The fifth edition of the Student Pugwash USA internship directory. It highlights approximately 200 organizations that work to promote the ethical use of science and technology and provides suggestions on how to go about the internship and job search.

• **Science, Technology, and Ethical Priorities: Proceedings of Student Pugwash USA's Ninth International Conference**.

• **Pugwatch.** The chapter newsletter.

• **Chapter Organizing Guide.** Provides chapter members with an A to Z guide to getting a campus-based chapter up and running.

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