

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

Volume II • Number Two • October 1997 • Student Pugwash USA

## exploring human genetics

Dolly, the now-famous sheep clone, is one example of the profound capabilities made possible by advances in the field of genetics. Each human being is composed of three billion bits of information organized into about 100,000 genes. Genes encode messages passed from parent to offspring that are translated into traits such as eye color, gender, and baldness. The catalogue of known human genes, the Online Mendelian Inheritance in Man database, lists 5,600 sites of genetic mutations and more than 420 medical conditions in the human genome. By studying genes, researchers may be able to provide answers to some of the most basic questions of life and death.

The study of genetics began with Mendel's experiments with garden peas in 1865 and stole headlines with Dolly's appearance in 1997. The idea that humans can control characteristics passed from one individual to another has sparked interest and debate for many years. International initiatives to map the location and determine the sequence of all human genes promise to advance several fields, including biotechnology and medicine. In addition, the discovery of genes associated with some genetic diseases may help doctors predict which patients are at risk.

Although genetics is studied in several disciplines, its social and ethical consequences have yet to be fully explored. The potential for misuse of genetic information is significant and has led to the development of laws and regulations to limit its use. Debate continues on cross-species organ transplantation and the insertion of human genes into animals or bacteria to produce biochemicals, such as insulin. Researchers disagree on the role genetics plays in determining our propensity for obesity and other conditions. As genetic advances accelerate, society will continue to grapple with increasingly complex issues.

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.

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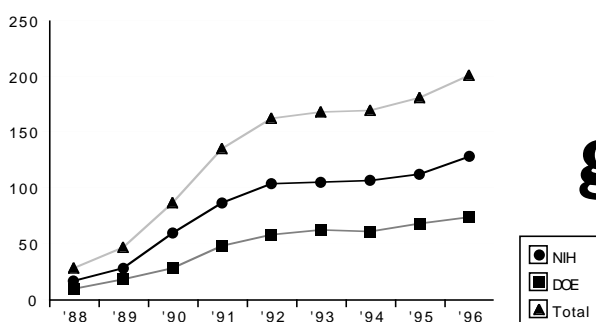
U S A

# go figure!

The uses of genetic information are increasing as new discoveries appear almost daily. As society grapples with the meaning and possibilities of using genetic engineering (recombining pieces of DNA) to alter the course of disease, explain complex behaviors, and produce clones of animals, surveys show that the public is uncertain whether genetics will change things for the better or for the worse.

The effort to map the human genome is an international one, with a number of countries contributing to the goal of understanding this basic element of life. While DNA sequencing technologies have become more sophisticated and the genomes of less-complex organisms have already been mapped, the enormous size of the human genome makes this a formidable task. The US mapping project, the Human Genome Project, is progressing at a rapid rate, utilizing millions of dollars each year, and forcing debate on issues with unexplored consequences.

## human genome project funding in the usa (millions of dollars)



	'88	'89	'90	'91	'92	'93	'94	'95	'96
National Institutes of Health	17.2	28.2	59.5	87.4	104.8	106.1	107.6	112.6	127.9
Department of Energy	10.7	18.5	27.9	47.9	58.7	62.5	62	69	74
Total	27.9	46.7	87.4	135.3	163.5	168.6	169.6	181.6	201.9

↑ **Source:** *Human Genome News*, Human Genome Management Information System, Oak Ridge National Laboratory, Correspondence, July 9, 1997.

	benefits outweigh risks	benefits equal risks	risks outweigh benefits
Americans attentive to science and technology	64%	16%	20%
Americans attentive to medical research	55%	17%	27%
All adults	43%	22%	35%

↑ **Source:** *Science & Engineering Indicators 1996*, National Science Board, National Science Foundation, Washington, DC: US Government Printing Office, 1996. Note: In this graph, attentiveness is used to indicate individuals who display "a high level interest," "believe they are well informed," and "reveal a minimal pattern of information acquisition." The responses were in answer to this question, posed in 1995: "Some persons have argued that the creation of new life forms through genetic engineering research constitutes a serious risk, while other persons have argued that this research may yield major benefits for society. In your opinion, have the benefits of genetic engineering research outweighed the harmful results, or have the harmful results of genetic engineering research been greater than its benefits?"

## countries with human genome research programs (1997)

- Australia
- Brazil
- Canada
- China
- Denmark
- European Union
- France
- Germany
- Israel
- Italy
- Japan
- Korea
- Mexico
- Netherlands
- Russia
- Sweden
- United Kingdom
- United States

↑ **Source:** *Human Genome News*, Human Genome Management Information System, Oak Ridge National Laboratory, Correspondence, August 15, 1997.

# gene genies?

## do the benefits of genetic engineering outweigh the risks?

# in control or out of it ?

Since the 1970s, presidential commissions and advisory boards have examined the ethics of biomedical research. These panels have addressed controversial issues, such as genetic testing and the use of human subjects and embryos in research. They generally include scientists, religious leaders, economists, philosophers, lawyers, and other concerned citizens. The commissions issue recommendations for government agencies that may serve as the basis for policy initiatives.

President Clinton issued a ban on human cloning immediately following the reports of Dolly. He also requested the National Bioethics Advisory Commission to review the ethical and legal issues surrounding human cloning. The commission's June 1997 report, *Cloning Human Beings*, states that it is "morally unacceptable" to try to create a child through cloning. It recommends continuance of the existing moratorium on federal funds to clone humans, urges the private sector to comply with this ban, and calls for legislation to formally extend this ban to the private sector. Rules severely restrict using federal funding for human embryo research, although they only place a few limitations on the private sector. Some fear that the US ban on cloning will only encourage the development of unregulated projects in other countries.

The federal government is also involved in genetics through the coordination of the Human Genome Project (HGP), which began in the mid-1980s. The Department of Energy and the National Institutes of Health undertook the initial planning stages to map the genome in 1988. In 1990, the agencies formally began a 15-year, \$3 billion research program to provide funds to researchers across the country to locate all human genes. In addition to mapping and sequencing the genes, the HGP was designed to generate new biomedical technologies, create research databases and computerized analysis tools, yield information about genes that cause illness, and train students and scientists. As part of the HGP, the Ethical, Legal, and Social Implications program supports research projects on the implications of identifying genes and gaining knowledge of their interaction. The ultimate goal of the HGP is to complete the sequence of the genome by the year 2005. Currently, the project is slightly ahead of schedule and under budget.

## nerds' words

**bioethics\***—originally . . . encompassing an examination of the ethics of all biological sciences. With time . . . has become synonymous with biomedical ethics.

**cloning**—the technique of producing a genetically identical duplicate of a cell or organism.

**DNA**—deoxyribonucleic acid. The chemical within each cell that stores genetic information. Copies of these chemicals are passed from parent to child and form the basis of heredity.

**DNA sequence**—refers to the linear array of nitrogenous bases (four chemical structures that occur in a DNA molecule that impart its genetic storage capability) in a single strand of a DNA molecule; a gene may consist of a linear arrangement of hundreds to thousands of bases.

**gene**—a unit of heredity; a segment of DNA containing the code for a specific product or function.

**genome**—a complete set of the genetic information inherited from one's parents. Everyone has two complete sets of this information, one inherited from the mother, one from the father. All cells in the body carry this genetic information.

**marker gene**—a gene that causes a known trait and which is located nearby a gene of interest (perhaps a disease gene).

**mutation**—a change in the number, arrangement, or molecular sequence of a gene.

\*Definition taken from *Biomedical Ethics in US Public Policy—Background Paper*, OTA-BP-BBS-105, US Congress, Office of Technology Assessment, Washington, DC: US Government Printing Office, June 1993.

All other definitions are taken from *Exploring Public Policy Issues in Genetics*, Mark S. Frankel (editor), Washington, DC: American Association for the Advancement of Science, 1997.

### **taking the test . . .**

A genetic disease may develop if a gene contains a mutation that causes a serious malfunction. People can get genetic diseases in two ways—from a parent's genes or from damage to their own genes after birth. Tests can offer a predictive diagnosis of these diseases by detecting the presence of a marker gene, the levels of certain enzymes or other chemicals, or by direct detection of mutations. Blood tests can reveal whether a person has genes associated with Alzheimer's or other brain diseases and certain forms of cancer. Each technique used in genetic testing has limitations that must be considered. While the tests indicate the relative likelihood of disease development, the information is complex and can be misconstrued. People contemplating genetic testing should pursue adequate counseling when making this decision. Early testing is important when the disease has treatment options, but some diseases have no treatment or cure and testing can affect some of the most important decisions in life.

The information provided by genetic tests can be used in a variety of ways and many instances of genetic discrimination have surfaced. Insurance companies have denied or limited health care benefits based on the results of genetic tests. Employers have discriminated against potential employees because they fear higher insurance premiums and loss of work days. Partial protection against discrimination in health insurance through the use of genetic information was enacted last year and new laws prohibiting additional forms of discrimination in both health care and life insurance are on the way.

### **. . . and changing the answers**

The introduction of normal genes into a cell to alleviate or cure inherited and acquired diseases is known as gene therapy. This revolutionary, but highly experimental, therapy is a promising new option for the treatment of diseases like cystic fibrosis (CF), the most common lethal inherited disease in the United States. Clinical trials in humans with CF are underway in an effort to correct a gene mutation that causes mucous to thicken and collect in the lungs. Among acquired diseases, clinical trials are also underway to cure women afflicted with a particular type of breast cancer associated with the mutation of a gene identified in 1994. Although gene therapy is a major medical advance, there are no guarantees that this technique will cure these diseases.

### **my genes made me do it?**

In recent years there has been an effort to determine the degree of genetic influence on behavior. Many believe that certain behaviors result from the combination of genetic and environmental factors. There are highly debated reports that schizophrenia, alcoholism, sexual preference, obesity, and violence all have genetic components which may predispose a person to a certain behavior. Some scientists see this as a way for people to avoid taking responsibility for their actions. Other researchers believe genetic predisposition is an explanation for some of the most complex behaviors, such as why one person becomes addicted to a drug and another does not.

### **hello, hello, dolly, dolly!**

Dolly was the first animal cloned from an adult cell, making her the world's most famous and controversial sheep. The concept of applying this process to create human clones has fostered a serious debate among politicians, scientists, and ethicists. Although cloning techniques have been used for decades, the idea of cloning humans previously remained in the realm of science fiction. Benefits of cloning to individuals and society range from generating organs that can be transplanted without rejection to preserving genetic lineage. Society would also face new relationships within families, as one's parent could be genetically one's twin. Those opposed to cloning humans cite difficulties for the clone, including the loss of individuality and dignity, as well as undetermined health risks. Following Dolly's arrival, President Clinton issued a ban on the use of federal funds for human cloning. Abroad, the reaction has been similar—Argentina, Australia, Denmark, Germany, Great Britain, and Spain support prohibiting such experimentation. Both the European Commission's Bioethics Advisory Panel and the World Health Organization deem cloning of humans to be unethical and French President Chirac urges an international ban. The technique is still in its infancy and, until there is an ethical balance between the risks and benefits, human cloning may remain on the pages of sci-fi novels.

# (anything but a) conclusion

Genetics is a broad field that encompasses a number of ethical dilemmas and touches our lives daily. Our health insurance, our employment prospects, our medical care, and the decisions we make about becoming a parent are all affected by the ability to decipher the information in our genes. The prospect of being able to clone animals raises the specter of cloning humans. As a society, we are charged with deciding which uses of this technology are appropriate. The ethics of using genetic information for the purpose of helping people or discriminating against them is not a receding issue. This is only the beginning.

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

Do you believe that the potential benefits of human cloning outweigh the negative aspects of genetically duplicating a person? What benefits can you imagine from allowing clones of people like Albert Einstein or Michael Jordan? What would be the dangers? How should we determine who should be cloned and what criteria should be used to make that decision?

Recent experiments have introduced human cells into animals in an effort to produce organs that will not be rejected when transplanted into humans. Where would you draw the line? Would you support continued efforts to produce human organs in animals? Should some animals, such as primates, be excluded from these experiments? Why or why not?



The Human Genome Diversity Project (HGDP) has made efforts to map DNA from indigenous peoples—despite the opposition to the project of representatives of 18 indigenous organizations. Do you believe that the HGDP is a positive step to preserve the unique qualities of racial or ethnic diversity or is it an intrusive and exploitative intervention into other cultures? There is some debate over who will benefit economically from any resulting patents. Who do you believe should reap profits generated from the use of indigenous peoples' DNA? Do you think that ownership of the human genome by way of patents is analogous to the ownership of people?

The Human Genome Project has a budget of \$3 billion over 15 years. Do you believe that the funding allocated for the HGP is well-spent or should it be used to build hospitals, expand public transportation, extend the Head Start program, or other initiatives? If you were managing the HGP budget, would you focus on finding all the genes or would you look for specific genes associated with diseases?



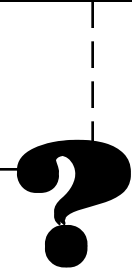
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• Screening for many genetic diseases is done by testing for the presence of a marker gene located close to the disease-associated gene. While many tests have a high degree of accuracy, the test is based on the likelihood that the disease may develop. Would you be tested, even if you knew you could learn that you may develop a fatal disease for which there is no cure? What factors would you consider in making your decision?

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If it is shown that genes have a substantial effect on certain behaviors, such as obesity, addiction, sexual orientation, etc., do you believe that a genetic predisposition for certain behaviors would explain and justify the practice of those behaviors? Do you believe that finding a gene for a certain behavior will lead to greater or lesser acceptance of people associated with that behavior? Why or why not?

Given the high cost of health insurance, do you believe that insurance companies or current employers should be able to gain access to employees' genetic information? Do you see any potential for misuse of this information? Do you think that companies should have access to such information about prospective employees? Why or why not?



*In utero* screening for some diseases, such as Down Syndrome, has been done for many years. With the identification of genes and their function, it may be possible to screen a fetus for other diseases, conditions, or predispositions. If you or your partner were pregnant, under what conditions would you want to test the fetus for potential diseases? Under what conditions, if any, would you decide to terminate the pregnancy? Do you see any potential for misuse of such capabilities?

Gene therapy is an experimental technique at this point and yet it promises to provide a cure for many life-threatening genetic diseases. Do you believe that more emphasis should be placed on developing gene therapy treatment methods? What are the benefits and drawbacks to accelerating this process, especially in the case of fatal illnesses? Where would you place the priority—diseases that are life-threatening, diseases affecting children, or other diseases?



What role do developed countries have in bringing genome research, genetic screening, and gene therapy to the developing world? Do developed countries have a responsibility to research genetic diseases primarily affecting people in developing countries?

**the gene scene**

- *Altered Fates: Gene Therapy and the Retooling of Human Life*, Jeff Lyon and Peter Gorner—an easy read for those familiar with medicine as well as its history. New York: W.W. Norton Company, 1996.
- *Biomedical Ethics in US Public Policy*, Office of Technology Assessment—a good outline of the basics of bioethics and the lessons learned from past initiatives. Washington, DC: US Government Printing Office, 1993.
- *Brave New World*, Aldous Huxley—(novel) a must-read classic about the not-so-distant future of science and genetics. New York: Harpers and Brother, 1932.
- *The Code of Codes: Scientific and Social Issues in the Human Genome Project*, Daniel J. Kelves and Leroy Hood (editors)—an informative discussion on human genetics. Cambridge, MA: Harvard University Press, 1992.
- *Cloning Human Beings: Report and Recommendations of the National Bioethics Commission*—the most recent recommendations for government and corporate policy on human cloning from the presidential commission. Rockville, MD: National Bioethics Advisory Commission, 1997.
- *Exploding the Gene Myths: How Genetic Information is Produced and Manipulated by Scientists, Physicians, Employers, Insurance Companies, Educators, and Law Enforcers*, Ruth Hubbard and Elijah Wald—kind of techy but explodes with knowledge of genetics. Boston, MA: Beacon Press, 1997.
- *Exploring Public Policy Issues in Genetics*, Mark S. Frankel (editor)—covers a variety of issues in genetics. Washington, DC: American Association for the Advancement of Science, 1997.
- *Genethics*, David Suzuki and Peter Knudtson—bridges the gap between science and ethics. Cambridge, MA: Harvard University Press, 1990.
- *The Gene Wars: Science, Politics, and the Human Genome*, Robert Cook-Deegan—detailed, interesting account of the HGP from an insider's perspective. New York: W.W. Norton Company, 1994.
- "Gene Therapy: How it Will Work Against Cancer, AIDS, Alzheimer's and More," *Scientific American*, Volume 276, Number 6, June 1997.
- "The Genome Issue," *Science Magazine*, Volume 274, Number 5287, October 26, 1997.
- *Human Genome News*, Betty K. Mansfield (editor)—a newsletter for people interested in genome research. On the Web at <http://www.ornl.gov/hgmis>.
- *Los Alamos Science*, Necia Grant Cooper (editor)—a great resource. Los Alamos, NM: Los Alamos Science, 1992.
- *Mapping Our Genes: The Genome Project and the Future of Medicine*, Lois Wingerson—a very good read, touches home on the issues of genetic diseases and the family. New York: Plume Printing, 1990.

**check it out !****the gene screen**

- *Alien Terminator*—five miles below earth, a group of scientists are perfecting a series of DNA experiments that can change the world, but one of the experiments goes awry, 1995.
- *The Fly (I and II)*—a scientist (Jeff Goldblum) develops the technique to hybridize human (his own) and insect genes. In the sequel, his son, born of the human fly, is employed at the same laboratory and performs research. The entire laboratory waits for his mutant genes to be expressed, 1989.
- *The Island of Dr. Moreau*—Dr. Moreau (Marlon Brando) has successfully combined human and animal DNA to make crossbreeds. As expected, something goes wrong, 1996.
- *Jurassic Park and The Lost World*—if you don't know what these are about, go back to sleep, 1993 and 1997.
- *Multiplicity*—Michael Keaton stars in this light-hearted film about a guy who finds that there are not enough hours in the day, so he decides to clone himself. He does not anticipate that each clone will have a different personality, 1996.
- *The Nutty Professor*—an incredibly obese college professor (Eddie Murphy) is on the verge of a breakthrough in DNA restructuring, 1996.
- *Pinky and the Brain*—(cartoon) laboratory mice with spliced genes try desperately to overthrow the Earth, 1995.

**cyberspace****top picks**

- Human Genome Project Information (this is a cool site with links to virtually every organization, support group, laboratory, and database dealing with genetics)—[http://www.ornl.gov/TechResources/Human\\_Genome/home.html](http://www.ornl.gov/TechResources/Human_Genome/home.html)
- Nature Genetics Magazine (check out the past and present issues of this magazine)—<http://www.genetics.nature.com>

**mark your gene sites!****best of the rest**

- American Association for the Advancement of Science (offers cool genetics video, check the Education and Human Resources Department)—<http://www.aaas.org>
- American Society of Human Genetics—<http://www.faseb.org/genetics/ashg/ashgmenu.htm>
- Council for Responsible Genetics—<http://www.essential.org/crg/>
- DOE Human Genome Program—[http://www.er.doe.gov/production/ober/HELSSRD\\_top.html](http://www.er.doe.gov/production/ober/HELSSRD_top.html)
- The Gene Letter (an electronic newsletter on genetics and public policy)—<http://www.geneletter.org>
- Human Genome Organization (international organization of scientist who promote international collaboration of the HGP)—<http://hugo.gdb.org>
- National Center for Genome Resources (nonprofit organization focusing on genetic resources)—<http://www.ncgr.org>
- National Human Genome Research Institute (formerly the National Center for Human Genome Research)—<http://www.nhgri.nih.gov>
- National Institutes of Health (check out the search engine for genetics information)—<http://www.nih.gov>

This **mind•full** was written by Constance Lassiter and Susan Higman. Constance is the New Careers and Pledge Coordinator at Student Pugwash USA. Susan is a PhD candidate at Johns Hopkins University and former Associate Director of Student Pugwash USA. Special thanks to Constance Pechura and Robert Cook-Deegan, Institute of Medicine, for their comments. Any errors are the responsibility of Student Pugwash USA. ©1997 Student Pugwash USA.

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## 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. Issues available this fall: the Pugwash Conferences; beyond nuclear weapons.
- **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.
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