

Required Extra Reading for Bio Sci 97, Genetics, 2007

University of California, Irvine

You are responsible for this material for the exam. Note that I will try very hard to avoid questions based on picky details. The questions are more likely to be based on "bigger" concepts, for example, the distinction between reproductive and therapeutic cloning.

Notes: I provide links to remainder of the three articles for those of you who are interested. However, I do not require that you read the remainder of the three articles. Also, sometimes I provide links to various web sites. These are included for those who wish to explore a particular topic, but I do not require that you visit those web sites; they are optional.

- Prof. Lee Bardwell

Arguments Against Creating Human Clones

1. Human cloning would foster an understanding of children, and of people in general, as objects that can be designed and manufactured to possess specific characteristics. Human cloning would diminish the sense of uniqueness of an individual. It would violate deeply and widely held convictions concerning human individuality and freedom, could lead to a devaluation of clones in comparison with non-clones.

Rebuttal: This will be true only if we allow it to be true. There is no reason that individuals and society can't learn to embrace human clones as just one more element of human diversity and creativity.

4. Human cloning is inherently unsafe. 95-98% of mammalian cloning experiments have resulted in failures in the form of miscarriages, stillbirths, and life-threatening anomalies. It could not be developed without putting the physical safety of the clones and the women who bear them at grave risk.

Rebuttal: Every medical technology carries with it a degree of risk. Cloning techniques will eventually be perfected in mammals and will then be suitable for human trials.

Arguments in Favor of Creating Human Clones:

1. Human cloning can provide genetically related children for people who cannot be helped by other fertility treatments (i.e., who do not produce eggs or sperm).

Rebuttal: The number of men and women who do not produce eggs or sperm at all is very small. If it could be perfected and used for this limited group, it would be all but impossible to prevent its use from spreading. Further, this argument appropriates the phrase "genetically related" to embrace a condition that has never before occurred in human history, one which abolishes the genetic variations that have always existed between parent and child.

2. Human cloning could allow parents of a child who has died to seek redress for their loss.

Rebuttal: Throughout history, parents who have lost children have grieved and sought consolation from family and community. "Replacing" the deceased child by cloning degrades and dehumanizes the child, its replacement, and all of us.

3. Human cloning is a reproductive right, and should be allowed once it is judged to be no less safe than natural reproduction.

Rebuttal: Rights are socially negotiated, and no "right" to clone oneself has ever been established.

Reasons for Concern about Therapeutic Cloning

1. Perfection of techniques to create clonal human embryos would make it more difficult to prevent the births of human clones.

Rebuttal: We can pass strong laws making reproductive cloning illegal without banning research cloning.

2. Perfection of cloning techniques would open the door to even more powerful technologies of human genetic modification such as "designer babies".

Rebuttal: If society wishes to ban inheritable genetic modification it can and should do so.

3. Large scale therapeutic cloning could generate a market for women's eggs that could easily lead to exploitation.

Rebuttal: First, this might not happen. Second, as long as women give informed consent and are fairly compensated, perhaps markets in human eggs should not be seen as a bad thing.

Reasons to Support Therapeutic Cloning

1. Cloned embryos are said to be needed for research on embryonic stem cells that promise to revolutionize medicine. Scientists believe that embryonic stem cell research will lead to cures for many diseases and will provide tissues and organs for

transplant and treatment of degenerative conditions.

Rebuttal: Stem cell research does not require therapeutic cloning

2. Research cloning will be necessary in order to produce compatible tissues and organs for patients being treated with stem cell therapies. In order to overcome the immune rejection problems associated with organ and tissue transplants, stem cells would have to be obtained from embryos produced from a patient's own cells, by means of research cloning.

Rebuttal: Therapeutic cloning may not be necessary to overcome immune rejection after stem cell therapy. And it will be way too expensive to make custom stem cells for every patient.

For more information:

<http://www.genetics-and-society.org>

March 9, 2005

U.N. Backs Human Cloning Ban

by Colum Lynch
The Washington Post

The U.N. General Assembly adopted a declaration Tuesday that calls on governments to ban all forms of human cloning that are "incompatible with human dignity and the protection of human life."

The U.S.-backed resolution, which passed by a vote of 84 to 34 with 37 abstentions, is not legally binding. The vote ended four years of highly contentious debate toward a legally binding treaty -- an effort that unraveled when the participants could not agree.

The dispute pitted the United States and conservative Catholic countries, which favor a total ban, against many European, Asian and other governments, which want a partial ban that would permit the cloning of human embryos for stem cell research. Virtually all U.N. members agree that the cloning of humans should be banned.

Sichan Siv, the U.S. delegate, welcomed the action by the 191-member General Assembly in a brief statement.

Britain, Belgium, China and other countries that support "therapeutic cloning" -- the cloning of human embryos in medical research aimed at finding cures for diseases -- said they will not honor the declaration.

"The United Kingdom is a strong supporter of therapeutic cloning research because it

has the potential to revolutionize medicine in this century in the way that antibiotics did in the last," said Emyr Jones Parry, Britain's U.N. ambassador.

Diplomats and experts on cloning said that the language in Tuesday's declaration was ambiguous and that its meaning would be disputed. For example, it is unclear whether therapeutic cloning is considered "incompatible with human dignity."

Still, a number of U.S. and European medical and scientific groups expressed dismay over Tuesday's vote, saying it could undercut medical research aimed at curing a host of diseases, including Parkinson's, Alzheimer's and diabetes.

Biotech Soybeans Plant Seed of Risky Revolution

Stephanie Simon
L.A. Times
July 1, 2001

CHESTERFIELD, Mo.--For nine years, two dozen genetic engineers struggled to create a simple soybean that would stand up to a killer herbicide.

After tens of thousands of mistakes, they thought they might have done it: They had created 100 seedlings laced with DNA from soil bacteria, a cauliflower virus and a petunia plant. They planned to test them cautiously in their Monsanto Co. labs. But an eager executive decided to test them all, to douse every plant with a highly potent concentration of the herbicide.

The team leader, Stephen Padgett, raced to the greenhouse to plead that some seedlings be spared. But he was too late; the plants were sprayed.

Every one of them survived.

They would go on to become the first blockbuster biotech crop, sweeping across America's farms and into America's diet with astounding speed.

Genetically modified soy has been on the market just five years. Yet it already accounts for two-thirds of the U.S. soybean harvest. Soy products are used in hundreds of processed foods, often to add texture and protein. So the biotech beans end up in pancake mix and baby formula, chicken soup and margarine, crackers and salad dressing, ice cream and granola bars. Monsanto's scientists have also engineered two-thirds of all the cotton and a quarter of all the corn grown in the United States.

>From lab to field to table, the story of engineered soy offers a window into the biotechnology revolution. It was the first staple crop to be successfully engineered and

widely planted. And it offers the longest-running case study of the biotech experiment.

Five years in, there are signs that the rapid spread of transgenic crops may be upending agricultural ecosystems--throwing colonies of soil microbes out of balance and shifting the types of weeds that crop up most often on fertile fields.

The reason for Monsanto's success is straightforward: The new seed is easier and often cheaper to grow. It can reduce the need for chemicals to control weeds and pests.

Transgenic soy, cotton and corn are now planted on more than 75 million acres in every state except Alaska, Hawaii, Nevada and Rhode Island. Most U.S. livestock eat feed made with biotech grain. And 70% of processed foods have biotech ingredients. Despite bitter European protests, the crops are increasingly popular overseas as well, especially in parts of Asia and South America.

Monsanto executives see genetic engineering as a wonder tool that can help alleviate hunger by making food more nutritious and easier to grow. They take their triumph with these first few crops as proof that they can change the world. Their critics fear just that.

The Search

Biotech soy was born of a business brainstorm.

In the late 1970s, as today, Monsanto's leading product was a herbicide called Roundup, which is made from glyphosate, an incredibly effective chemical that kills almost everything green. Farmers worldwide relied on Roundup to clear their fields before planting. But they could not spray it once their seeds sprouted, because it would kill their crop along with the weeds.

Monsanto set out to boost sales of Roundup by creating crops that would tolerate glyphosate.

It would take 700,000 hours of work.

Padgett's team spent the first seven years on the wrong track altogether, trying to rearrange soybean DNA by hand. "At a certain point," Padgett recalled, "we decided we needed to think outside the box."

Instead of toying with soy's existing genes, they decided to try to add new ones. Glyphosate works by binding to an enzyme in plants that produces proteins critical for growth. With the glyphosate clinging to it, the enzyme can't function and the plant dies. Bacteria have that same critical enzyme. So in 1987, Padgett's group began screening bacteria to see whether any had a natural resistance to glyphosate.

Two years later, with the help of a robot that ran analyses all night, they found one that

did. In this bacterium, the enzyme critical for growth had a slightly different chemical structure, so glyphosate could not bind to it. It was, Padgett said, "a great Eureka moment."

Not that he allowed time to celebrate. Working late nights, jazz music blaring, the team turned to the hardest chore: figuring out how to make the bacterial DNA perform its magic in soy.

The key turned out to be a gene packet containing DNA from four sources.

A gene from a cauliflower virus acted as a master control switch. It activated the bacterial enzyme that was able to fend off Roundup while still producing adequate growth proteins. A snippet of petunia DNA made sure those proteins were ferried to the proper location within the soy plant. Another strand of DNA from a different type of bacterium served as a molecular stop sign, preventing overproduction of the proteins.

Padgett's team bundled those four strands of DNA together. Then they used a gene gun to plug the whole packet into individual soybean cells. The process worked like this: DNA strands were wrapped around tiny gold pellets, smaller than dust. The gene gun then fired the pellets at soybean embryos. As the pellets ripped through the embryo, at velocities of up to 1,400 feet per second, the DNA was wiped off, sticking in the nuclei of individual cells.

Trouble was, the gene gun inserted the DNA at random. Sometimes a bundle would splinter before landing in a cell. Or two gene packets would double up. Even worse, the DNA would at times land in a spot that interfered with cellular function. The team had to fire the gun tens of thousands of times to get a few dozen plants that looked promising.

After three years of field tests on these promising plants, a single line of transformed soybean shone as superior. It could resist heavy doses of glyphosate, as the greenhouse experiment proved. And it looked great in the field, matching conventional varieties bean-for-bean in yield, growth and quality. "It was bulletproof," Padgett recalled with pride. In 1993, Monsanto declared it a winner.

The embryo that had been labeled "40-3-2" during the gene-gun trials had emerged as the first transgenic soybean. Monsanto called it "Roundup Ready," because it could be sprayed with the herbicide and suffer no harm.

The Concerns

In 1996, their first year on the market, Roundup Ready beans were planted on 1 million acres. The next year, that figure was up to 9 million. The year after, 27 million. This year, the USDA projects biotech soybeans will be sown on 48 million acres. Monsanto estimates 90% of soy growers have tried them, though some have rejected them as not cost-effective for their particular fields.

The transgenic soy (and, later, corn and cottonseed oil) entered the food stream so quickly that most processors did not even realize they were using it. It was not until Europeans began protesting "Frankenfoods" that U.S. makers of processed food began to investigate the safety of ingredients they had been using for at least two years.

"We really learned after the fact, after these ingredients were already in the food supply," said Lisa Katic, director of scientific policy for the Grocery Manufacturers of America.

After a year of intense review, Katic said her group's members are convinced the biotech crops on the market today are safe to eat. And, indeed, no serious scientist has suggested otherwise.

Instead, five years after the introduction of Roundup Ready soy, many critics are turning their attention to the beans' performance in the field--and to possible environmental effects.

Monsanto says its research shows its beans perform every bit as well as conventional varieties. They also have some positive environmental spinoffs. Farmers do not have to churn the soil as much to loosen weeds, which cuts down on erosion. And because glyphosate is so effective, soybean growers have slashed both the number of chemicals they spray and the number of fuel-burning trips they take across their fields.

But there have been some worrisome indicators too.

Research from the University of Georgia suggests that the genetic changes may have affected the soybean metabolism, causing stalks to grow brittle and split in extreme heat. A study at the University of Arkansas found some biotech beans fared badly in drought, perhaps because the Roundup spray damaged the soil bacteria that help soy plants draw in nutrients.

Perhaps most troubling, USDA soil scientist Robert Kremer found in a four-year study that spraying Roundup over biotech beans seemed to touch off wild proliferation of fungi in the soil. Some fungi are fatal to soybeans. But Kremer says it's not short-term crop damage that concerns him. It's long-term shifts in soil ecology if Roundup is sprayed season after season on our most fertile fields.

"These microbes in the soil are in a natural balance with each other, and if we keep putting the same chemicals in year after year, that could lead to a shift in the soil ecosystem, which could lead to problems down the road in terms of the soil's ability to nurture plant life," Kremer said. Monsanto says it is still studying the issue.

Of equal concern are the shifts some farmers have noticed in weed populations.

Since the introduction of Roundup Ready crops, glyphosate use has soared. It was applied on 20% of U.S. farm acreage in 1995; four years later, on 62%. (Though there are competing brands from other companies, the boom has been a windfall for Monsanto: Roundup sales brought in \$2.6 billion last year.) Some farmers now plant Roundup Ready crops year-round, rotating corn and soybeans; they may apply glyphosate four to six times a year on a single field.

Though the EPA has determined that spraying crops with Roundup has no ill effect on the consumer, critics worry that such heavy use will speed the emergence of weeds that can tolerate glyphosate--and will force farmers and home gardeners alike to turn to more toxic herbicides.

Some farmers are starting to see morning glory vine and yellow nut sedge, the weeds Roundup has always had the toughest time controlling, moving aggressively into their fields. Some need to mix other herbicides with their glyphosate for total weed control, said Don Schafer, a soybean product manager at Pioneer Hi-Bred International, a major seed company.

"By the time the industry acknowledges a problem, the glyphosate-resistant genes will have spread far enough through the weed population that not much can be done," warns Charles Benbrook, a biotech critic who directs the Northwest Science and Environmental Policy Center in Sandpoint, Idaho. "This is not the kind of thing where you can put the genie back in the bottle."

Monsanto executives point out that Roundup has been on the market for 25 years and there are only two confirmed examples of weeds that can withstand it: one in Australia and one in Malaysia. (They are studying two other recent reports of tolerant weeds in Delaware and Missouri, however.) What's more, they say, Roundup has long been applied four to six times a year on tropical crops such as Florida citrus, without sparking widespread weed shifts.

Many growers, however, seem resigned that weeds will one day outsmart Roundup. "It's happened with every herbicide we have," said Don Latham, an Iowa farmer.

That conviction doesn't stop him from using Roundup Ready beans, though. In fact, Latham loves them. With conventional soy, he makes two passes over each field to spray three different herbicides--and still spends hours pulling stray weeds by hand. With the biotech crop, he sprays glyphosate once and kills every weed. Even factoring in the higher price of Roundup beans, he saves \$22.50 an acre on chemicals and fuel. To him, biotech is a bargain.

Those who fueled this revolution, who spent nights analyzing soil bacteria in the lab and days juggling test tubes with a robot, think of Roundup Ready as a marvel. It has been a profit machine for Monsanto, of course. But they say it has transformed farming as well. They are proud, and still slightly amazed, that they pulled it off.

Padgette tried recently to put the feeling into words. This was the best he could do: "You just sit back and you say, 'Wow.'"

Glowing red GM fish to sell in US

24 November 2003
NewScientist.com news service
Shaoni Bhattacharya

The GM fish glow even brighter under ultraviolet light

A tropical fish that fluoresces bright red is set to become the first genetically modified pet to go on sale in the US. Alan Blake and colleagues at Yorktown Technologies LP say the GloFish will be available from January 2004.

The little zebra fish were originally developed by researchers in Singapore to signal the presence of water pollutants by changing colour. "These fish were bred to help fight environmental pollution," Blake told Reuters. "They were bred to fluoresce in the presence of toxins."

Blake and the scientists who developed the GM fish, which especially glows under ultraviolet light, say they pose no threat to the environment as they cannot survive in non-tropical waters. However, the news of the GM aquarium pet has sparked concern among conservationists.

Food-safety and conservation groups have sent a joint letter to the US Food and Drug Administration urging immediate intervention. "If FDA somehow fails to regulate the proposal of Yorktown Technologies ... it will set a precedent for all other (genetically engineered) fish producers, and the floodgates will almost literally be opened," wrote Andrew Kimbrell, executive director of the Center for Food Safety.

Gene promoters

Zebra fish are normally black and silver in colour. But Gong Zhiyuan and colleagues at the National University of Singapore have been developing as pollution indicators by genetically manipulating the fish to fluoresce in different ways.

The GloFish was produced by injecting zebra fish eggs with the gene of a sea anemone which makes it red coloured. The researchers have also produced green fish by injecting the eggs with a fluorescent marker gene from jellyfish, which is commonly used in experiments.

To enable the fishes' use as pollution detectors, the scientists have pinpointed gene promoters which act as on/off switches in the presence of certain triggers. One type of

switch is activated by the sex hormone oestrogen, which can contaminate water. Other glow switches can be stress-induced and will respond to the presence of damaging chemicals like heavy metals.

Zhiyuan says as many as five colours could be added to zebra fish to light up in the presence of different pollutants. He believes that using the glowing fish as ornamental pets should not pose an environmental threat if released into the wild.

"Fluorescent transgenic fish do not have any apparent fitness advantage over wild type fish of the same species," he says. "To the contrary, because fluorescence carries additional burdens in biosynthesis, energy distribution, and predator avoidance, fluorescent fish are likely to have reduced fitness."

Lab creates 'long-distance mouse'

Friday, 2 November 2007

BBC News

A genetically modified "supermouse" which can run twice as far as a normal rodent has been created by scientists working in the US.

It also lives longer, and breeds later in life compared with its standard laboratory cousin.

The research has been conducted at Case Western Reserve University in Cleveland, Ohio.

Details of the scientists' new transgenic animals are published in the Journal of Biological Chemistry.

The mice were produced to study the biochemistry at play in metabolism and could aid the understanding of human health and disease.

The GM rodents can run five to six kilometres at a speed of 20 meters per minute on a treadmill, for up to six hours before stopping.

"They are metabolically similar to Lance Armstrong biking up the Pyrenees; they utilise mainly fatty acids for energy and produce very little lactic acid," said Professor Richard Hanson, the senior author on the journal article.

He told BBC News: "The muscles of these mice have many more mitochondria. These are the little 'engines' in the cell that produce energy. For some reason, the number of mitochondria are around 10 times more than we see in the muscle of their littermates."

The mice over-express a gene responsible for the enzyme phosphoenolpyruvate carboxykinases (PEPCK-C). Normal expression is in the liver, in the production of glucose.

The scientists found their new mice would eat twice as much as normal mice - but weigh half as much. They could also give birth at three years old - which in human terms is akin to an 80-year-old woman giving birth.

Other research groups have produced similar novel rodents by altering different aspects of their genetics. One criticism of the work is that it could open the door to abuse, with the spectre of athletes resorting to gene therapy to try to improve their performance.

But Professor Hanson played this down. "Right now, this is impossible to do - putting a gene into muscle. It's unethical. And I don't think you'd want to do this. These animals are rather aggressive, we've noticed."

Scientists say such work is more likely to help them understand human conditions, such as those which lead to wasting of the muscles.

Breakthrough in primate cloning

Wednesday, 14 November 2007

BBC News

Experts have for the first time created cloned embryos from an adult monkey - a technical breakthrough that could bring efficient human cloning a step closer.

A team in the US created dozens of cloned embryos from a 10-year-old male macaque, the journal Nature reports. The work is being hailed as the first convincing evidence that therapeutic cloning is possible in primates.

The results of the American team could make it easier to clone human embryos for use in research. It raises the prospect of developing transplant tissues to treat diseases such as diabetes and Parkinson's that will not be rejected by the body.

The American group was able to extract stem cells from some of the cloned monkey embryos, persuading them to develop into mature heart and nerve cells in the laboratory.

Medical Promise

There had been a worry that primates may prove to be difficult in terms of cloning.

This would have been a huge setback for researchers working to develop new medical therapies based on embryonic stem cells.

In cloning to obtain stem cells, DNA from an adult animal is inserted into an unfertilized egg that has had its own genetic material removed. The egg is then encouraged to grow into an early embryo, from which stem cells can be extracted.

These stem cells, and the tissues that develop from them, will be a genetic match to the source of the DNA. In this case, the male macaque monkey.

Because stem cells are the forerunners of all tissues in the body, scientists hope they might one day be able to use these progenitors to create transplant tissues that are genetically matched to patients with degenerative conditions - such as diabetes - without the fear of rejection by the body.

Human cloning has been dogged by technical difficulties and controversies over faked research.

In 2004, a South Korean team announced that it had created the first cloned human embryos and extracted stem cells from them. But the study was later retracted when it emerged the lead author, Dr Hwang Woo-suk, had fabricated his work.

The only other published example of a human embryonic clone was created at Newcastle University, UK. But the clones survived for only a few days and did not produce any stem cells.

Human cloning clues

The technique used to generate the cloned macaque embryos is called somatic cell nuclear transfer (SCNT). This is the same basic procedure used to create Dolly the sheep and other cloned mammals.

But the lead author of the latest study, Dr Shoukhrat Mitalipov, has pioneered a novel way of handling the donor eggs during the cloning process.

In order to remove DNA from the eggs, scientists sometimes dye the genetic material or use an imaging technique that exposes the cell to ultraviolet light.

However, Dr Mitalipov and his colleagues believe both of these could damage primate eggs. Instead, they used an illumination technique which allowed the scientists to efficiently remove the cell's nucleus without resorting to the traditional approaches.

The new technique, called Oosight, uses polarised light to visualise microscopic cells in real time. The scientists found this resulted in a much improved survival rate for developing clones.

'Convincing evidence'

In a statement, Professor Alison Murdoch and Dr Mary Herbert, of the North-East England Stem Cell Institute (NESCI), said the work "provides the first convincing evidence that nuclear reprogramming is feasible in primates".

They added: "This is a very exciting development which takes us several steps closer to the production of patient-specific stem cells to treat life-limiting conditions such as Parkinson's, motor neurone disease, Huntington's disease and cystic fibrosis.

"By providing proof of principle in a primate model, Dr Mitalipov and his colleagues have made an important step towards realising the therapeutic potential of nuclear transfer in humans."

Professor Ian Wilmut, director of the Scottish Centre for Regenerative Medicine at the University of Edinburgh, commented: "Cloned cells produced with the genetic material of a patient who has inherited a disease would have the abnormalities associated with the disease."

The researcher, who led the project which resulted in Dolly the sheep, added: "The methods in this paper are a significant step towards this objective."

Implantation efforts

But the development was not welcomed by everybody.

Josephine Quintavalle, director of the campaign group Comment on Reproductive Ethics (Core) told BBC News: "Bringing a clone to term is the only way to show that the cloned tissue is safe."

Ms Quintavalle pointed out that clones were not the only potential source of embryonic stem cells, and that other options such as cord blood existed.

The scientists behind the latest work reportedly tried to implant about 100 cloned embryos into the wombs of around 50 surrogate female macaques. However, their efforts did not result in the birth of any offspring.

But one author of the study said this could be down to bad luck. For example, Dolly the sheep - the first clone of an adult mammal - was only created after 277 attempts.

Dr Mitalipov is affiliated to the Oregon National Primate Research Center and the Oregon Stem Cell Center.

GENETIC DISCRIMINATION

The Burlington Northern Case – Workplace genetic testing

In 2000, the Burlington Northern Santa Fe Railroad Company began secret genetic testing of some of its workers, whom had sought worker's compensation and medical attention for carpal-tunnel syndrome. The workers claimed that they had not given consent nor did they know about the genetic tests. One worker alleged that he was threatened with losing his job if he did not comply with testing.

The genetic tests were designed to find a mutation in a gene called PMP 22, which is the cause of a condition called Hereditary Neuropathy with liability to Pressure Palsies (HNPP). HNPP causes a person to be susceptible to nerve injury from pressure, stretch or repetitive use and can lead to carpal tunnel syndrome.

When the workers found out about the genetic testing, they, their unions, and the Equal Employment Opportunity Commission (EEOC) filed suit. They contended that Burlington Northern conducted the tests to avoid financial responsibility for treating or compensating the workers' carpal tunnel conditions.

The suit was settled out of court in May 2002. Burlington Northern agreed to pay \$2.2 million to the workers.

German teacher fights genetic discrimination

13 October 2003

A teacher in Germany who has been refused a permanent job because a genetic disorder runs in her family is now fighting the decision in court, the British Medical Journal reported last week. The woman, who has relatives affected by Huntington's disease (HD), was rejected for a job on the grounds that she was at high risk of developing the illness herself.

Under German employment law, government authorities can apparently reject job applicants on the ground of ill health, to minimise absenteeism and save money. HD is a genetic condition that causes progressive damage in certain areas of the brain, leading to gradual physical, emotional and mental changes. Symptoms of HD usually appear between the ages of 30 and 50 years, and people with the disease have a 50 per cent chance of passing it on to each of their children. The doctor who carried out the health check on the teacher reported that she was fit to perform her job, but that there was a 'higher risk' of future absenteeism because members of her family have HD.

Victims of genetic discrimination speak up

New Scientist Magazine
06 November 2005

Evidence is growing that employers and insurers are discriminating against people whose genes make them susceptible to serious disease

In the most complete survey yet of possible discrimination, around 1 in 12 people who have taken a genetic test said they had been disadvantaged as a result - for example, by being denied appropriate life insurance.

The survey is part of the pioneering Genetic Discrimination Project, which is attempting to document the extent of genetic discrimination in Australia and help any victims seek redress. A team led by Kristine Barlow-Stewart, who heads the Centre for Genetics Education in Sydney, analysed questionnaires filled in by more than 1000 people who had taken predictive tests for serious diseases, such as neurodegenerative disorders and cancer.

Initial results show that more respondents felt they had benefited from the test than claimed to have lost out.

US Senate passes genetic discrimination bill

21 February 2005

The US Senate has unanimously approved a bill that would ban employers and insurers from using genetic information. Senators voted 98-0 in favour of the bill last Thursday, although it now faces an uncertain future in the House of Representatives. In 2003, the Senate passed a nearly identical bill by 95-0, but the legislation was never voted on by the House.

Many individual states have already passed laws banning genetic discrimination. In October 2003, the US Senate approved the Genetic Information Nondiscrimination Act, after seven years of negotiation. However, the legislation was never brought to a vote in the House of Representatives.

A business coalition lead by the US Chamber of Commerce says that there is no evidence of workplace discrimination based on genetic information. It claims that basing laws on potential problems of this nature is 'fraught with opportunities for unintended consequences, unnecessary regulation and unwarranted litigation'.

The new bill has the support of the White House.

Update on genetic discrimination bill - Nov 2007

To become law, a bill must pass in both the Senate and the House of Representatives, and be signed by the president.

The current version of the bill is called "The Genetic Information Nondiscrimination Act of 2007". It has passed in the house but has not yet come up for a vote in the Senate. The chances that it will be voted on this year are slim.

To track the progress of this bill, go to
<http://www.govtrack.us/congress/bill.xpd?bill=s110-358>

U.S. military practices genetic discrimination in denying benefits

Those medically discharged with genetic diseases are left without disability or retirement benefits. Some are fighting back.

By Karen Kaplan
Los Angeles Times
August 18, 2007

Eric Miller's career as an Army Ranger wasn't ended by a battlefield wound, but his DNA.

Lurking in his genes was a mutation that made him vulnerable to uncontrolled tumor growth. After suffering back pain during a tour in Afghanistan, he underwent three surgeries to remove tumors from his brain and spine that left him with numbness throughout the left side of his body.

So began his journey into a dreaded scenario of the genetic age.

Because he was born with the mutation, the Army argued it bore no responsibility for his illness and medically discharged him in 2005 without the disability benefits or health insurance he needed to fight his disease.

"The Army didn't give me anything," said Miller, 28, a seven-year veteran who is training to join the Tennessee Highway Patrol.

While genetic discrimination is banned in most cases throughout the country, it is alive and well in the U.S. military.

For more than 20 years, the armed forces have held a policy that specifically denies

disability benefits to servicemen and women with congenital or hereditary conditions. The practice would be illegal in almost any other workplace.

There is one exception, instituted in 1999, that grants benefits to personnel who have served eight years.

"You could be in the military and be a six-pack-a-day smoker, and if you come down with emphysema, 'That's OK. We've got you covered,' " said Kathy Hudson, director of the Genetics and Public Policy Center at Johns Hopkins University. "But if you happen to have a disease where there is an identified genetic contribution, you are screwed."

Representatives from the Pentagon declined multiple requests to discuss the policy.

A high cost

The regulation appears to have stemmed from an effort to protect the armed services from becoming a magnet for people who knew they would come down with costly genetic illnesses, according to Dr. Mark Nunes, who headed the Air Force Genetics Center's DNA diagnostic laboratory at Keesler Air Force Base in Mississippi.

The threat is almost certainly small. A 1999 military analysis estimated that about 250 service members are discharged each year for health problems involving a genetic component. Disability payments for them would amount to \$1.7 million the first year and rise each year after that as more veterans join the rolls. Healthcare expenditures would have added to the tab.

"Maybe they didn't want to foot the bill for my disability," said Miller, whose rare genetic disease is called Von Hippel-Lindau syndrome. "It's saving money for them. I'm just one less soldier that they have to dish out compensation to."

But the cost for individuals medically discharged can be high. While some eventually receive benefits from Veterans Affairs or private insurers, the policy leaves Miller and others scrambling to find treatment for complex medical conditions at the same time they are reestablishing their lives as civilians without having the benefit of Tricare, the military's health insurance.

"It seems particularly draconian to say, 'Well, you're out with no benefits,' whereas another person with the same injury gets the coverage simply because we don't know there's a gene in there that's causing this," said Alex Capron, a professor who studies healthcare law, policy and ethics at USC.

The fear of genetic discrimination coincides with early efforts to decode the human genome more than 25 years ago.

It took no great insight to realize that a complete inventory of life's building blocks would not only revolutionize the practice of medicine, but also mark individuals whose

genes put them at risk for myriad diseases.

Congress took action in 1996, banning genetic discrimination in group health plans, and in 2000, President Clinton signed an executive order forbidding the practice against the federal government's nearly 2 million civilian employees. Similar laws against genetic discrimination swept through 31 states.

Congress is working to extend the federal law with the Genetic Information Nondiscrimination Act, which would protect people with individual medical policies. The act has passed the House and awaits a vote in the Senate.

Even if it becomes law, it will not apply to military personnel.

The Defense Department's original policy did not consider genetics when determining whether a soldier deserved medical retirement, assuming that any disease discovered during service had been incurred in the line of duty.

There was little reason to consider genetic mutations, since few were known. But by 1986, as scientists associated more sections of DNA with particular diseases, the military declared that it was not responsible for soldiers with "congenital and hereditary" conditions.

At the urging of the National Human Genome Research Institute, the Defense Department proposed in 1999 that anyone who had served for 180 days be eligible for medical retirement, even if their health problem had a genetic component, said Barbara Fuller, assistant director for ethics at NHGRI, part of the National Institutes of Health.

But the Office of Management and Budget decided on the longer, 8-year term to conform with other military health and retirement guidelines, according to an OMB official.

Some genetic discrimination is unavoidable given the demands of military service, said Nunes, now a geneticist at Ohio State University.

"If you have achondroplasia -- if you're a dwarf -- you're not eligible for military service," he said. "If you have hereditary hearing loss, you're not eligible for military service. If you have color blindness, you're not eligible to fly an airplane. Obviously, there's genetic discrimination in the military, for good reason."

But Nunes said the armed forces' disability policy was flawed by a fundamental misunderstanding about the biology of inherited diseases.

Only in a few cases, such as Huntington's disease, does a specific mutation in a particular stretch of DNA guarantee the onset of illness.

In most cases, a faulty gene increases an individual's risk of developing a disease, but does not ensure it. Typically, an external event is necessary to trigger the onset of a medical condition.

Such was the case with an Army helicopter gunship pilot who was reassigned to desk duty after she became too pregnant to fly.

Dr. Melissa Fries, an Air Force geneticist who became involved in the case, said the pilot developed a blood clot in her leg -- a typical complication of pregnancy that is exacerbated by inactivity.

She was diagnosed with chronic thrombophlebitis, a condition that disqualified her from flying. The pilot, who declined to discuss her case, decided to retire from the Army.

As part of her medical work-up, doctors discovered she had a genetic mutation for Factor V Leiden, which is found in 5% of Caucasians and increases their risk of developing blood clots.

An Army physical evaluation board, which determines disability benefits, denied her claim because of the mutation.

Her military doctors were stunned since her thrombophlebitis was probably caused by her pregnancy and desk job. They downplayed the role of her mutation because 99% of Factor V Leiden carriers never develop blood clots.

Testing discouraged

Military doctors now discourage their patients from getting potentially life-saving genetic tests, undermining their ability to provide top-notch care.

"If someone called me up with regard to genetic testing, I had to say, 'That might not be something you want to pursue,'" Nunes said. "That's very hard to say."

In her 26 years in the Air Force, Fries said she often dissuaded women from getting tested for the BRCA1 and BRCA2 mutations that dramatically increase their risk of developing breast cancer.

She recalled counseling a 22-year-old soldier whose father had just been diagnosed with Huntington's disease. The soldier had 50-50 odds of developing the disease.

A neurologist at Walter Reed Army Medical Center ordered a genetic test for Huntington's, and it turned up positive.

"He was discharged from the military on the basis of the Huntington's disease gene even though, at that level of gene expansion, there was expected to be another 25

years before he would display any symptoms," said Fries, now director of genetics and fetal medicine at Washington Hospital Center in Washington, D.C.

For many in the military, the best course is to simply refuse all genetic tests, even though they may be needed for an accurate diagnosis, she said.

Getting genetic tests through civilian channels is not an option because it would violate the uniform code of military justice.

"You could get court-martialed if it were revealed that you had sought medical treatment or testing outside the system," Nunes said.

Most soldiers have no idea about the genetic rule, much less have a reason to challenge it. For those who choose to fight, it can be arduous process.

No one contested the policy until Marine Gunnery Sgt. Jay Platt did in 1998.

Platt had lost an eye and a testicle to Von Hippel-Lindau syndrome before doctors told him he had a malignant tumor in his left kidney and four benign tumors on his brain. He knew his 15-year Marine career was over.

"If you want to go ahead and medically retire me, I'm not going to fight it," he told his doctors.

But the Marines refused. Instead, he was medically discharged without any benefits because his genetic disease was a preexisting condition.

A discharge have would cut Platt off from Tricare, which allows members to seek care from a large network of providers, just like a civilian HMO.

"That was my biggest thing," he said. "I needed to have treatments for the rest of my life."

With the help experts from NHGRI, Platt appealed his case to an physical evaluation board. His doctors said that although the mutation predisposed him to Von Hippel-Lindau syndrome, some aspect of his service -- such as repeated exposure to the solvents used to clean weapons -- could have triggered the tumors.

Platt ultimately won his case and was granted disability payments of about \$2,000 a month. He now travels the country as a motivational speaker talking about his fight against his disease.

The helicopter pilot with the Factor V Leiden mutation also appealed her case, going all the way to the Army surgeon general to win a medical retirement.

But Miller, the Army ranger, did not fare so well. Even though he had the same

disease as Platt, he lost his appeal and was discharged without benefits in 2005.

He still has to monitor his slow-growing tumors and be on the lookout for new ones. But without Tricare coverage, he can't afford to see a civilian doctor close to his home in Oak Ridge, Tenn.

Instead, he travels an hour and a half to the Veterans Affairs facility in Johnson City at least twice a year. Every so often, he makes the three-hour drive to another VA facility in Lexington, Ky., to see a neurologist with expertise in his disease.

The worry never leaves him. His genes guarantee that he will never be cured.

Facing Life With a Lethal Gene

By AMY HARMON
The New York Times
March 18, 2007

The test, the counselor said, had come back positive.

Katharine Moser inhaled sharply. She thought she was as ready as anyone could be to face her genetic destiny. She had attended a genetic counseling session and visited a psychiatrist, as required by the clinic. She had undergone the recommended neurological exam. And yet, she realized in that moment, she had never expected to hear those words.

"What do I do now?" Ms. Moser asked.

"What do you want to do?" the counselor replied.

"Cry," she said quietly.

Her best friend, Colleen Elio, seated next to her, had already begun.

Ms. Moser was 23. It had taken her months to convince the clinic at NewYork-Presbyterian Hospital/Columbia University Medical Center in Manhattan that she wanted, at such a young age, to find out whether she carried the gene for Huntington's disease.

Huntington's, the incurable brain disorder that possessed her grandfather's body and ravaged his mind for three decades, typically strikes in middle age. But most young adults who know the disease runs in their family have avoided the DNA test that can tell whether they will get it, preferring the torture - and hope - of not knowing.

Ms. Moser is part of a vanguard of people at risk for Huntington's who are choosing to learn early what their future holds. Facing their genetic heritage, they say, will help them decide how to live their lives.

Yet even as a raft of new DNA tests are revealing predispositions to all kinds of conditions, including breast cancer, depression and dementia, little is known about what it is like to live with such knowledge.

"What runs in your own family, and would you want to know?" said Nancy Wexler, a neuropsychologist at Columbia and the president of the Hereditary Disease Foundation, which has pioneered Huntington's research. "Soon everyone is going to have an option like this. You make the decision to test, you have to live with the consequences."

-- That is the end of the section of this article that you are required to read. However, if you wish to read more of this article, go to <http://www.nytimes.com/2007/03/18/health/18huntington.html>

I also recommend (as optional reading) the following articles, also on the topic of how to deal with information on one's alleles.

Cancer Free at 33, but Weighing a Mastectomy
<http://www.nytimes.com/2007/09/16/health/16gene.html>

My Genome, Myself: Seeking Clues in DNA
<http://www.nytimes.com/2007/11/17/us/17dna.html>

These and other interesting articles on genetics can be found at <http://topics.nytimes.com/top/news/national/series/dnaage/>

What is Eugenics?

Eugenics is a discredited pseudoscience given birth (in its modern form) by Francis Galton (a cousin of Charles Darwin), who coined the term in 1883. It proposes that the human race could be improved by selective breeding. To encourage the reproduction of those with qualities seen as beneficial is known as positive eugenics. To discourage the reproduction those with qualities seen as undesirable is known as negative eugenics. Most eugenicists were not, and are not, geneticists. The eugenics movement reached its peak of popularity in the U.S. in the decade before World War II. Eugenics has been used to justify many horrific things, including (in the U.S.) the forced surgical sterilization of people judged to be mentally ill or retarded, epileptic, criminal, alcoholic, or immoral; and (in Nazi Germany) the execution of

millions of people so as to "purify the race". California was home to an extensive eugenics movement in the twentieth century, with approximately 20,000 sterilizations performed, most before the end of World War II. Incredibly, forced sterilization continued in some U.S. states up until the late 1970s, as can be seen by reading the articles below.

Just Regret For Sterilizations

LYNCHBURG, Virginia, Feb. 15, 2001

In the 1940s, the state labeled Raymond W. Hudlow a "mental defective" and surgically sterilized him.

Years later, his nation honored him as a war hero, awarding him the Bronze Star for valor, the Purple Heart and the Prisoner of War Medal for service in World War II.

Now the Virginia General Assembly has refused to apologize to Hudlow and the more than 7,400 other Virginians sterilized under the state's eugenics program between 1924 and 1979. Instead, the state Senate voted Wednesday to express "profound regret" for the General Assembly's action 77 years ago that led to forced sterilizations.

Although eugenics eventually was discredited as political and social prejudice rather than scientific fact, neither Virginia nor any of the 29 other states that conducted eugenical sterilizations has ever compensated or apologized to the more than 60,000 victims.

The Virginia law was upheld by the U.S. Supreme Court in 1927. That ruling, which still stands, led a federal judge in 1984 to throw out a class-action lawsuit filed by eugenics victims of the state.

Virginia's Southern aristocracy, acting under a eugenics law that served as a model for the rest of the nation - and for Adolph Hitler - tried to purify the white race from 1924 to 1979. Targeted was virtually any human shortcoming believed to be a hereditary disease that could be stamped out by surgical sterilization, such as mental illness, mental retardation, epilepsy, criminal behavior, alcoholism and immorality.

Hudlow says the trauma inflicted on him when he was a teen-ager in the wards of the Virginia Colony for Epileptics and Feebleminded has never left him. He has more flashbacks about that time than the terror of combat and imprisonment by the Germans, he said.

Hudlow's malady: repeatedly running away from home to avoid beatings by his father. When his father told the "welfare lady" that "he couldn't control me," Hudlow said, his reproductive fate was sealed. He was 16 years old.

"I was picked up by the sheriff at home. He handcuffed me and took me" to the Colony near Lynchburg, where most of Virginia's sterilizations were performed. A county judge in 1942 granted the Colony's request to sterilize Hudlow, identified in the court order as an "inmate" of the Colony.

"They just came and got me before I woke up one morning. They wheeled me and threw me up on the operating table," he said.

No one explained what they were doing, Hudlow said. "The only way I found out, an employee on Ward 7 told me I wouldn't be able to father any children."

Sixteen months after the operation, Hudlow was released from the Colony and was drafted into the Army. He served as the radioman for his platoon leader, was wounded and spent seven months in German prison camps.

Hudlow decided to make the military a career and served 21 years in the Army and Air Force.

Phil Theisen, president of the Lynchburg Depressive Disorders Association, has urged state lawmakers to make a strong, clear apology to the eugenics victims.

"This is a skeleton in the closet for Virginia that will continue to be there until it's addressed forthright," Theisen said. "An apology would be a historic first, and that makes it all the more important."

While some lawmakers supported a strong apology by the state, others, including Virginia House member Mitchell Van Yahres, said it would only draw fire.

"It carries a connotation of guilt that I don't want to be associated with," Van Yahres said.

<http://www.cbsnews.com/stories/2001/02/15/national/main272199.shtml>

Oregon Apologizes For Sterilizations

SALEM, Ore., Dec. 2, 2002

Gov. John Kitzhaber formally apologized Monday for Oregon's past eugenics law that led to the forced sterilization of hundreds of people.

Girls in reform school, people in mental institutions and poor women selected by welfare workers were among the more than 2,500 Oregonians subjected to sterilizations under a law that stood from 1917 to 1983.

"To those who suffered, I say the people of Oregon are sorry," Kitzhaber said during a

ceremony in the governor's office. "Our hearts are heavy for the pain you endured."

He is the second governor to atone for state eugenics laws after Virginia Gov. Mark Warner, who also erected a memorial in May to the first woman sterilized under the policy.

Among the dozens of people who crowded into Kitzhaber's office for Monday's ceremony was Velma Hayes, 68, who was sterilized at age 15 while living at the Fairview Training Center, a state-run institution for the mentally ill and retarded.

Hayes called the state's acknowledgment of wrongdoing "long overdue," but praised Kitzhaber's effort to make things right.

"I want to thank you for taking the time to apologize," Hayes told the governor. "Your apology is appreciated and accepted."

Not everyone was satisfied. Ken Newman, 61, who said he was given a vasectomy without his consent when he was a teen living at Fairview, said the governor's remarks don't erase what happened.

"I want more than an apology. I want to be compensated," Newman said. The law was based on the pseudoscientific movement that sought to prevent people considered "unfit" or "defective" from having children. After 1967, the Oregon law was chiefly used to sterilize those with mental illness or mental disability.

Davis apologizes for state's sterilization program

Those with hereditary flaws were victims
- Paul Feist, Chronicle Sacramento Bureau
Wednesday, March 12, 2003

Sacramento -- In the archives at California Institute of Technology in Pasadena sit thousands of files that chronicle a shameful secret of California's past. The records are listed in clinical fashion: 4000-4392 Napa Sterilizations; 5000-5137 Agnews Sterilizations, and so on. Each tells the story of one of the 20,000 people sterilized at state hospitals -- often without consent -- during the early part of the last century.

On Tuesday (March 11 2003), Gov. Gray Davis became the latest governor to atone for the forced sterilization of patients, which was part of a selective breeding movement called eugenics.

California started performing forced sterilizations in 1909, and the practice trailed off after the end of World War II. Patients became candidates for involuntary sterilization if they were diagnosed with "lunacy," "feeble-mindedness," sexual deviancy, epilepsy and alcoholism, among other things.