Missouri criticized the incorporation of the principle, writing in a letter to President Bill Clinton that it "would, in effect, endorse the idea of making nonscience-based decisions about U.S. farm exports."

Is the precautionary principle consistent with science, which after all can never prove a negative? "A lot of scientists get very frustrated with consumer groups, who want absolute confidence that transgenic crops are going to be absolutely safe," says Allison A. Snow, an ecologist at Ohio State University. "We don't scrutinize regular crops, and a lot of inventions, that carefully."

Others don't see the precautionary principle as antithetical to the rigorous approach of science. "The way I usually think about it is that the precautionary principle actually shines a bright light *on* science," states Ted Schettler, science director for the Science and Environmental Health Network (SEHN), a consortium of environmental groups that is a leading proponent of the principle in North America. "We're talking about enormously complex interactions among a number of systems. Now we're starting to think that some of these things are probably unknowable and indeterminate," he says, adding that "the precautionary principle doesn't tell you what to do, but it does tell you [what] to look at."

The precautionary principle requires a different kind of science, maintains Carolyn Raffensperger, SEHN's executive director. "Science has been commodified. What we've created in the last 10 or 15 years is a science that has a goal of global economic competitiveness." As examples, Raffensperger cites a relative lack of National Institutes of Health spending on allergenicity and the environmental consequences of biotechnology, compared with funding for the development of transgenic products and cancer medicines. "Our public dollars go toward developing more drugs to treat cancer rather than doing some of the things necessary to prevent cancer," she complains.

For science to evolve along the lines envisioned by Raffensperger, researchers will have to develop a broader base of skills to handle the multifaceted data from complicated problems. National Science Foundation director Rita Colwell has been a strong proponent of the type of interdisciplinary work required to illuminate the complex scientific issues of today. The NSF specifically designed the Biocomplexity in the Environment Initiative in 1999 to address interacting systems such as global warming, human impacts on the environment, and biodiversity. Outlays have grown from an initial $25.7 million to $75 million for 2001.

Raffensperger also thinks the precautionary principle will require researchers to raise their social consciousness. "We need a sense of the public good" among scientists, she says. "I'm a lawyer, obligated to do public service. What if scientists shared that same obligation to use their skills for the good, pro bono? We think the precautionary principle invites us to put ethics back into science."

In fact, Jane Lubchenco called for just such a reorientation in her presidential address at the annual meeting of the American Association for the Advancement of Science in 1997. "Urgent and unprecedented environmental and social changes challenge scientists to define a new social contract," she said, "a commitment on the part of all scientists to devote their energies and talents to the most pressing problems of the day, in proportion to their importance, in exchange for public funding." Raffensperger notes that the U.S. has mobilized science in this way in the past with programs on infectious diseases and national defense, such as the Manhattan Project.

What is more, scientists whose work butts up against the precautionary principle will have "to do a very good job of expressing the uncertainty in their information," points out William W. Fox, Jr., director of science and technology for the National Marine Fisheries Service. This is difficult for some scientists, Fox notes, particularly in fisheries science, where uncertainty limits can be quite large. "You can't always collect data exactly like your statistical model dictates, so there's a bit of experience involved, not something that can be repeated by another scientist. It's not really science; it's like an artist doing it—so a large part of your scientific advice comes from art," he comments.

Those wide limits are the crux of the issue, the point at which proponents of the precautionary principle say decisions should be taken from the realm of science and into politics. "The precautionary principle is no longer an academic debate," Raffensperger stated at the Harvard conference. "It is in the hands of the people," as displayed, she argued, by demonstrations against economic globalization, seen most violently in Seattle at the 1999 meeting of the World Trade Organization. "This is [about] how they want to live their lives." —*David Appell*

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GENETICS_DISCRIMINATION

Pink Slip in Your Genes

Evidence builds that employers hire and fire based on genetic tests; meanwhile protective legislation languishes

In April 1999 Terri Seargent went to her doctor with slight breathing difficulties. A simple genetic test confirmed her worst nightmare: she had alpha-1 deficiency, meaning that she might one day succumb to the same respiratory disease that killed her brother. The test probably saved Seargent's life—the condition is treatable if detected early—but when her employer learned of her costly condition, she was fired and lost her health insurance.

Seargent's case could have been a shining success story for genetic science. Instead it exemplifies what many feared would happen: genetic discrimination. A recent survey of more than 1,500 genetic counselors and physicians conducted by social scientist Dorothy C. Wertz at the University of Massachusetts Medical Center found that 785 patients reported having lost their jobs or insurance because of their genes. "There is more discrimination than I uncovered in my survey," says Wertz, who presented her findings at the American Public Health Association meeting in Boston in November. Wertz's results buttress an earlier Georgetown University study in which 13 percent of patients surveyed said they had been denied or let go

from a job because of a genetic condition.

Such worries have already deterred many people from having beneficial predictive tests, says Barbara Fuller, a senior policy adviser at the National Human Genome Research Institute (NHGRI), where geneticists unveiled the human blueprint last June. For example, one third of women contacted for possible inclusion in a recent breast cancer study refused to participate because they feared losing their insurance or jobs if a genetic defect was discovered. A 1998 study by the National Center for Genome Resources found that 63 percent of people would not take genetic tests if employers could access the results and that 85 percent believe employers should be barred from accessing genetic information.

So far genetic testing has not had much effect on health insurance. Richard Coorsh, a spokesperson for the Health Insurance Association of America, notes that health insurers are not interested in genetic tests, for two reasons. First, they already ask for a person's family history—for many conditions, a less accurate form of genetic testing. Second, genetic tests cannot—except for a few rare conditions such as Huntington's disease—predict if someone with a disease gene will definitely get sick.

Public health scientist Mark Hall of Wake Forest University interviewed insurers and used fictitious scenarios to test the market directly. He found that a presymptomatic person with a genetic predisposition to a serious condition faces little or no difficulty in obtaining health insurance. "It's a nonissue in the insurance market," he concludes. Moreover, there is some legislation against it. Four years ago the federal government passed the Health Insurance Portability and Accountability Act (HIPAA) to prevent group insurers from denying coverage based on genetic results. A patchwork of state laws also prohibit insurers from doing so.

Genetic privacy for employees, however, has been another matter. Federal workers are protected to some degree; last February, President Bill Clinton signed an executive order forbidding the use of genetic testing in the hiring of federal employees. But this guarantee doesn't extend to the private sector. Currently an employer can ask for, and discriminate on the basis of, medical information, including genetic test results, between the time an offer is made and when the employee begins work. A 1999 survey by the American Management Association found that 30 percent of large and midsize companies sought some form of genetic information about their employees, and 7 percent used that information in awarding promotions and hiring. As the cost of DNA testing goes down, the number of businesses testing their workers is expected to skyrocket.

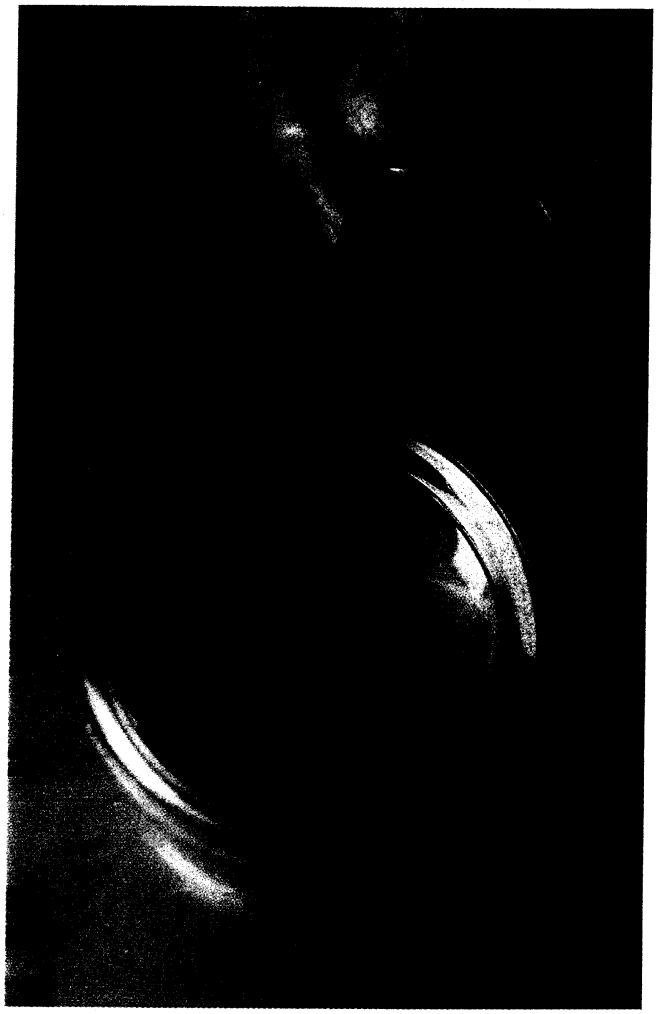
Concerned scientists, including Francis S. Collins, director of the NHGRI and the driving force behind the Human Genome Project, have called on the Senate to pass laws that ban employers from using DNA testing to blacklist job applicants suspected of having "flawed" genes. Despite their efforts, more than 100 federal and state congressional bills addressing the issue have been repeatedly shelved in the past two years. "There is no federal law on the books to protect [private-sector] employees, because members of Congress have their heads in the sand," contends Joanne Hustead, a policy director at the National Partnership for Women and Families, a nonprofit group urging support of federal legislation. "Your video rental records are more protected," she claims.

Wertz also believes that more laws are simply Band-Aids on the problem: "We need a public health system to fix this one." And she may be right. In nations such as Canada and the U.K., where a national health service is in place, the thorny issue of genetic discrimination is not much of a concern.

While policymakers play catch-up with genetic science, Seargent and others are hoping that the Equal Employment Opportunity Commission (EEOC) will help. The EEOC considers discrimination based on genetic traits to be illegal under the Americans with Disabilities Act of 1990, which safeguards the disabled from employment-based discrimination. The commission has made Seargent its poster child and is taking her story to court as a test case on genetic discrimination.

Seargent, who now works at home for Alpha Net, a Web-based support group for people with alpha-1 deficiency, doubts she'll be victorious, because all but 4.3 percent of ADA cases are won by the employer. She does not regret, however, having taken the genetic test. "In the end," she says, "my life is more important than a job." Ideally, it would be better not to have to choose. —*Diane Martindale*

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DETECTING A MISPRINT in your genes can alert you to potential diseases early enough for you to take preventive measures. But it can also get you fired, as surveys are showing. Legislation protecting private-sector employees has not gone anywhere.

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