

Rifkin's Latest Target: Genetic Testing

Jeremy Rifkin, the author-activist who's never met an engineered gene he liked, kicked off a new campaign against the use of human genetic data on 21 May in Washington, D.C. With endorsements from members of women's health movements in 69 nations, he unveiled a campaign that will attack the patenting of breast cancer genes BRCA1 and BRCA2 and push for new laws to limit access to human genetic data in research, medicine, and commerce.

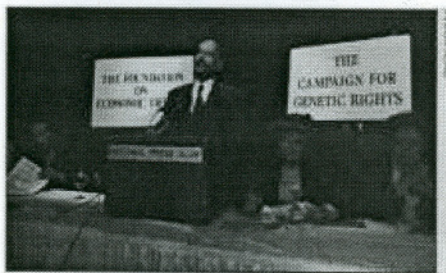
As a first step, Rifkin's group plans to file a petition with the U.S. Patent and Trademark Office (PTO) challenging patent claims filed by Myriad Genetics Inc. of Salt Lake City. And at the press conference, Representative Patsy Mink (D-HI) joined Rifkin to plug medical-privacy legislation, listing seven bills pending in Congress, including one introduced on 16 May by Representative Jim McDermott (D-WA). The McDermott bill—broader than other proposals designed to prevent discrimination in insurance—aims to give patients more control over medical records, including genetic-test data. It would forbid access to such records without the patients' informed consent and would impose civil and criminal penalties for unauthorized use of such data.

Rifkin's nonprofit organization, The Foundation on Economic Trends, has a history dating back to the 1970s of opposing the commercial use of DNA technology. Almost precisely a year ago, for example, Rifkin launched another venture—a "Joint Appeal Against Human and Animal Patenting," for which he obtained the signatures of leaders of more than 80 religious groups (*Science*, 26 May 1995, p. 1126). The signatories of what Rifkin had billed as "the broadest coalition of religious leaders in U.S. history" later revealed that their goals were diverse. Some were willing to accept "process patents" involving the use of genetic material, while others flatly opposed any patenting of gene sequence data.

A similar diversity may exist among members of women's groups that support the new campaign. For example, one patient who spoke at Rifkin's press conference, Carolyn Marks of the National Ovarian Cancer Coalition, said in a phone interview that she thinks genetic tests may prove useful, but wants them tightly controlled. "What really grabbed me was the threat to genetic privacy," she said. After being diagnosed with both breast and ovarian cancer, she signed up this year for genetic counseling at the Fox Chase Cancer Center in Philadelphia. She expects to receive test results in July, and she worries that members of her family could

be prevented from getting jobs or health insurance because of her decision to be tested. As for patenting BRCA1, Marks says that it "boggles [her] mind" that anyone could claim to have invented a gene, adding that it suggests "a new definition of chutzpah."

Other members of Rifkin's coalition, such as former congress member Bella Abzug, a



Coalition builder. Jeremy Rifkin, launching new campaign.

breast cancer survivor and president of the Women's Environment and Development Organization, vehemently denounced the practice of gene patenting. "Human genes are not for sale or profit," she said at the press conference: "Any attempt to patent human genetic materials by individuals, scientific corporations, or other entities is unacceptable." Rifkin himself insists that "everyone" is against patenting genes, primarily, he says, because patents make diagnostic tests more expensive.

Rifkin describes his new campaign as "the beginning of the genetic rights movement around the world." But the campaigners may have a hard time catching up with the gene

sequencers, who are already far down the road. According to PTO staffer John Doll, the government has issued 1500 patents on a variety of genes, including approximately 500 patents on human genes. And at least 100 more patent applications on human genes—some containing 5000 DNA sequences apiece—await PTO's review.

Among them are the patent applications that Myriad has filed on both BRCA1 and BRCA2. The foundation will challenge these patents, according to its attorney, Theodore Waugh, on grounds that the claims are too broad and are likely to discourage other researchers from working in the area.

Myriad's president and CEO, Peter Meldrum, says his company strongly supports efforts to protect privacy, noting that 13 genetic-privacy laws have already passed state legislatures and 12 more are pending. But he warns that a ban on patenting genes could make it difficult to attract money into risky test development projects. Myriad expects to launch a major marketing program for a BRCA1 test "in the second half of this year." As part of the effort, Meldrum says, Myriad is sending 30,000 physicians a detailed educational package on the fundamentals of genetic risks and a specific guide to interpreting cancer-gene tests. In addition, Myriad is cosponsoring clinical trials on the use of its tests with the Memorial Sloan Kettering Cancer Center in New York and the National Cancer Institute.

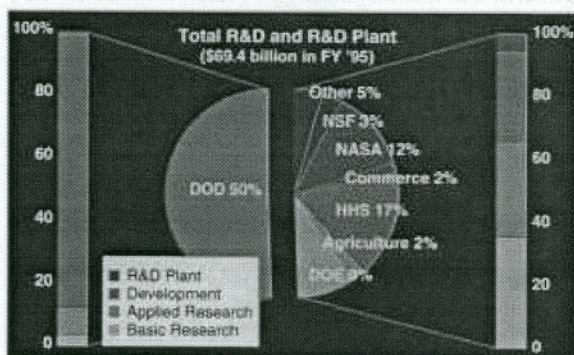
Meldrum notes that his company has invested "millions" in making its BRCA1 test definitive and comprehensive. Without patent protection on DNA sequences, he says, investors might not be willing to support such extensive R&D.

—Eliot Marshall

SCIENCE INDICATORS

How Federal Agencies Spend Their R&D

A basic difference. While the development of weapons systems absorbs most of the Defense Department's annual R&D budget, the rest of the federal government divides its R&D dollars fairly evenly among basic and applied research as well as development. This chart is one of hundreds that appear in the 1996 *Science and Engineering Indicators* report issued



last week by the National Science Foundation. A biennial compilation of statistics and analyses of the health of the U.S. research enterprise, including chapters on public attitudes toward science and international comparisons, *S&E Indicators* is available through the U.S. Government Printing Office (NSB 96-21).