includes coronary heart disease, stroke and peripheral vascular disease) will be the leading cause of death and disability until at least the year 2020, due largely to the increasing size of the aging population. Such a dramatic rise is not predicted for cancer or brain diseases, the panel noted. Yet research into the causes and treatment of the disease attracted only 8% of the 358 million ECU (\$481 million) allocated by the EU from 1994–1998. This compares with 12% for neurobiology and 10% for cancer.

This disparity is illustrated by the situation in the UK, where the largest sponsor of cardiovascular research is the British Heart Foundation (BHF). In 1996, the BHF spent 35 million pounds on research, considerably less than the 55 million pounds allocated to research by one of the major cancer-funding charities—the Imperial Cancer Research Fund.

John Martin

According to John Martin, BHF Professor of Cardiovascular Science at University College London, part of the problem lies in lobbying by other, powerful sections of the scientific community. But now, as the EU drafts its “fifth Framework” which will set research funding policy for 1998–2002, cardiovascular scientists are demanding that such “injustices” are not repeated.

As well as discussing funding priorities, the Rome delegates (selected for their track record in cardiovascular research over the past decade), emphasized three areas for future study: basic research, clinical trials and epidemiology/population studies. Speaking of the need for more investment into the basic biological mechanisms underlying cardiovascular disease, Martin gave the example of atherosclerosis. He noted that to erad-

icate this disease 100 years from now, “we really need to home in on the mechanisms of initiation—it’s too short-sighted to simply study treatments.”

Specific recommendations of the committee include more focus on gene therapy, research into the benefits of exercise and diet, and treatment of disease in women, the elderly and minority groups. Delegates acknowledged that there should be an emphasis on rehabilitation and disability, and that, in previous years, the quality of work from these areas has not been as high as from basic or clinical science.

In putting together these recommendations the European Community has, according to Martin, “committed itself to a co-operative effort to educate governments, physicians and professional societies across Europe about the ongoing need for a significant focus on cardiovascular research.” The focus may be there, but whether the funds will follow remains to be seen.

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Drug industry hopes to moderate genetic privacy laws

The increasingly public profile of genomic research has given rise to a fear that identification of mutations or inherited traits will lead to discrimination by insurers and misappropriation of DNA and other genetic material by pharmaceutical and biotechnology companies (*Nature Med* 3; 710 & 1056, 1997). In response to this fear, half the states in the U.S. have proposed or enacted laws to protect patients through informed consent, outright bans on discrimination or erection of barriers to ensure medical record privacy.

The eruption of new legislation has alarmed the drug industry, which says restricting the genetic information flow will slow basic research. Chief among the industry’s concerns are laws that make genetic information “personal property.” Last June, the states of New Hampshire and Oregon enacted laws dubbing genetic and medical data and/or tissue personal property that can not be used by insurers or researchers without express written permission from the patient. Now the drug industry trade group, the Pharmaceutical Research and Manufacturers of America (PhRMA), is lobbying intensively in those two states to reverse the statutes. “The whole idea of a property right is a bit of a gut reaction,” says Gillian Woollett, assistant vice president for biologics and biotechnology at PhRMA. She blames the trend to protect genetic information on

“fear of a loss of control.”

It’s a pervasive fear. Michigan, Delaware, Massachusetts, Nebraska and Maryland were considering similar property rights legislation. Rhode Island, Louisiana, and Georgia are expected to introduce similar bills in 1998. Florida repealed such a law this year and throughout 1997, PhRMA worked to amend or overturn property right proposals in Arkansas, Texas, Nevada, and New Mexico. This year it will increase efforts to ensure that well-intended laws to prevent insurance discrimination based on genetic test results do not prevent patients’ data from being accessed by researchers. The organization also expects to be busy confronting new efforts on Capitol Hill owing to the slew of ‘patients’ rights’ proposals introduced in this congressional session, which are intended to protect consumers and also include genetic privacy provisions.

PhRMA is advocating a compromise: informed consent for genetic material. This means that patients give permission for their blood, tissue or other material to be used by researchers as long as identifying information is removed. “Patient-anonymized data should be subject to free exchange,” says Woollett. She suggests a “gatekeeper”—a physician or a health insurer—could make sure that identifying information

is not released along with tissue samples. “They would have tremendous responsibility, of course,” says Woollett. And if a scientist needed to know more about a patient’s family history—whether a sibling or parent had an inherited trait—the investigator could go back through the gatekeeper, and presumably the patient, to request such information.

In November last year, the Centers for Disease Control and Prevention (CDC) resolved a two-year ethical dilemma surrounding archived DNA samples that researchers wanted to study. Patients who gave samples did not give permission for the material to be used in genetic research. The CDC will remove patient-identifying data and scientists will receive DNA only—not cells—and must return unused material. Woollett calls this proposal “very conservative and pretty damn safe for everybody,” although some believe it to be overcomplicated and unnecessary.

PhRMA believes that it is up to society to determine how genetic information is used, and hopes to persuade them that it should be used for research purposes so long as privacy is protected. “What we’re worried about is the idea that genetic information is bad stuff,” says Woollett. “Genetic information is good stuff.”

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