Genome Project Gets Rough Ride in Europe

German-led opposition in the European Parliament to human genome research could disrupt European-level programs

Brussels

PLANS TO FURTHER INTEGRATE European research efforts into the mapping and sequencing of the human genome are being given a rough ride by the European Parliament. A parliamentary committee last week proposed that the program should include substantial support for studies of the social and ethical implications of such research.

The Brussels-based European Commission, which coordinates the joint activities of the 12 member states of the European Economic Community (EEC), is preparing to launch a 3-year, $17-million program to increase cooperation among national genome research efforts and to find ways to integrate European efforts into any future collaborative project with U.S. scientists.

Commission officials say that the so-called "predictive medicine program" will pay careful attention to the social and ethical aspects of the research. But its top priority is to develop the "scientific and technological underpinnings" for the research.

However, critics in the European Parliament, the elected body that has an important role in influencing the Commission's activities, are arguing that the priorities should be adjusted, if not reversed. They believe that satisfactory answers should be found to some of the questions raised by the research before it is allowed to proceed.

A leading critic is Benedikt Härlin, a parliamentary representative of a group linked with the German Greens. "We are playing with the very substance of humankind and human dignity," he says. "It is crucial to have a proper understanding at this stage of the hazards which may be involved, and not get too euphoric about the research," he says.

Reflecting these views, the Energy, Research and Technology Committee of the Parliament last week added some substantial amendments, many written by Härlin, to the Commission's proposed program. The amendments stipulate that the program be broadened to include funding, for example, for a study of "the history of and current trends in eugenics" and for the preparation of a list of "possible and desirable measures to prevent the misuse of scientific knowledge of the human genome."

More specifically, the committee is proposing that "clear legal agreements" be concluded with individuals whose DNA is studied, covering "the nature of the use and study of their DNA and the rights of those concerned in respect of the use of the research results." Such individuals would include members of the new families proposed to be added to the 40 families now being studied by the Centre d'Etude du Polymorphisme Humaine (CEPH) in Paris in collaboration with the Howard Hughes Medical Institute.

As conceived by the Commission, the predictive medicine program has four major themes: improving the resolution of the human genetic map, setting up a network of ordered clone libraries, improving and diffusing advanced genetic technologies through EEC member states, and developing an integrated database and data-handling techniques.

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The amount of money involved is relatively small compared with various existing or planned national programs in countries such as France, Britain, Italy, and West Germany. The Commission's own efforts are therefore intended to be primarily catalytic. Anthony Dickens, head of the medical research division of the science, research and development directorate, talks about the need to use central resources to avoid "fragmentation" in European genome research, and to "coordinate what is happening in member states."

Members of the Parliament's research committee, whose amendments will be debated in a plenary session of the Parliament in Strasbourg on 14 February, say they are not opposed to these goals, or to the research itself.

Their main aim, they say, is to make sure that the research is properly regulated, and that its implications receive wide public discussion as early as possible.

"We are not trying to prevent this research from being carried out, but we want the scientific community to accumulate information about the possible consequences of this research before they begin to develop ways of applying it," says Härlin.

Commission officials say they would have difficulty in accepting some of the committee's more radical amendments to their proposals. They point out that they have already set up a working group on social and ethical aspects of genome research chaired by Ernst Winnacker, director of the molecular biology laboratory and head of the Gene Center at the University of Munich, which plans to hold at least one public meeting.

"We certainly want to make sure that everything which goes on in the program is conducted in an ethically acceptable way," says Dickens. "But we differ with the argument that you must foresee and resolve every legal and ethical eventuality before the research is allowed to start."

Härlin's point of view has its most vocal supporters in West Germany. Indeed, a national parliamentary committee in Bonn has expressed its opposition to the entire predictive medicine program. Last week, the Bundestag gave qualified approval to that position. Some observers in Brussels attribute Bonn's attitude to a lack of centralized medical research policy in West Germany and to a continuing "national guilt complex" about Nazi atrocities.

But concern about the possible implications of the research, particularly if it is motivated by industrial or commercial considerations, has sufficient support from political groups in other European countries to make the outcome of the Strasbourg debate unpredictable.

If the amendments opposed by the Commission are accepted by the full Parliament, it will be up to the Council of Ministers, the political body made up of representatives of the 12 member states, to decide on the final form of the research program.

But even if the parliamentary critics lose out in this process, their concerns are not expected to go away.

The Parliament is already scheduled, during a debate on embryo research and in vitro fertilization, to discuss a separate proposal from its legal affairs committee to establish an "international commission for the ethical, social, and political evaluation of human genome analysis." And individual members say they intend to keep up the pressure to establish what Härlin describes as "the conditions for genuine public involvement in the assessment of this research."

■ **DAVID DICKSON**