

Federal Support of R&D,  
National Academy of Sciences,  
Washington, DC 20418, USA

## References

1. *Allocating Federal Funds for Science and Technology* (National Academy Press, Washington, DC, 1995), p. 20.

The Institute of Scientific Information's (ISI's) analysis of citations to Department of Energy (DOE) labs and academia is an interesting starting point for comparing research quality, but it misses a critical point of institutional culture. In academia, all faculty members, even those without extramural funding, are under pressure to publish all results, even minor ones. In DOE labs, less important and less citable results are likely to be placed in technical reports that are not captured in ISI's database. A more appropriate comparison would be between publications from DOE labs and publications reporting results of university research funded by DOE.

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## Genetics and Informed Consent

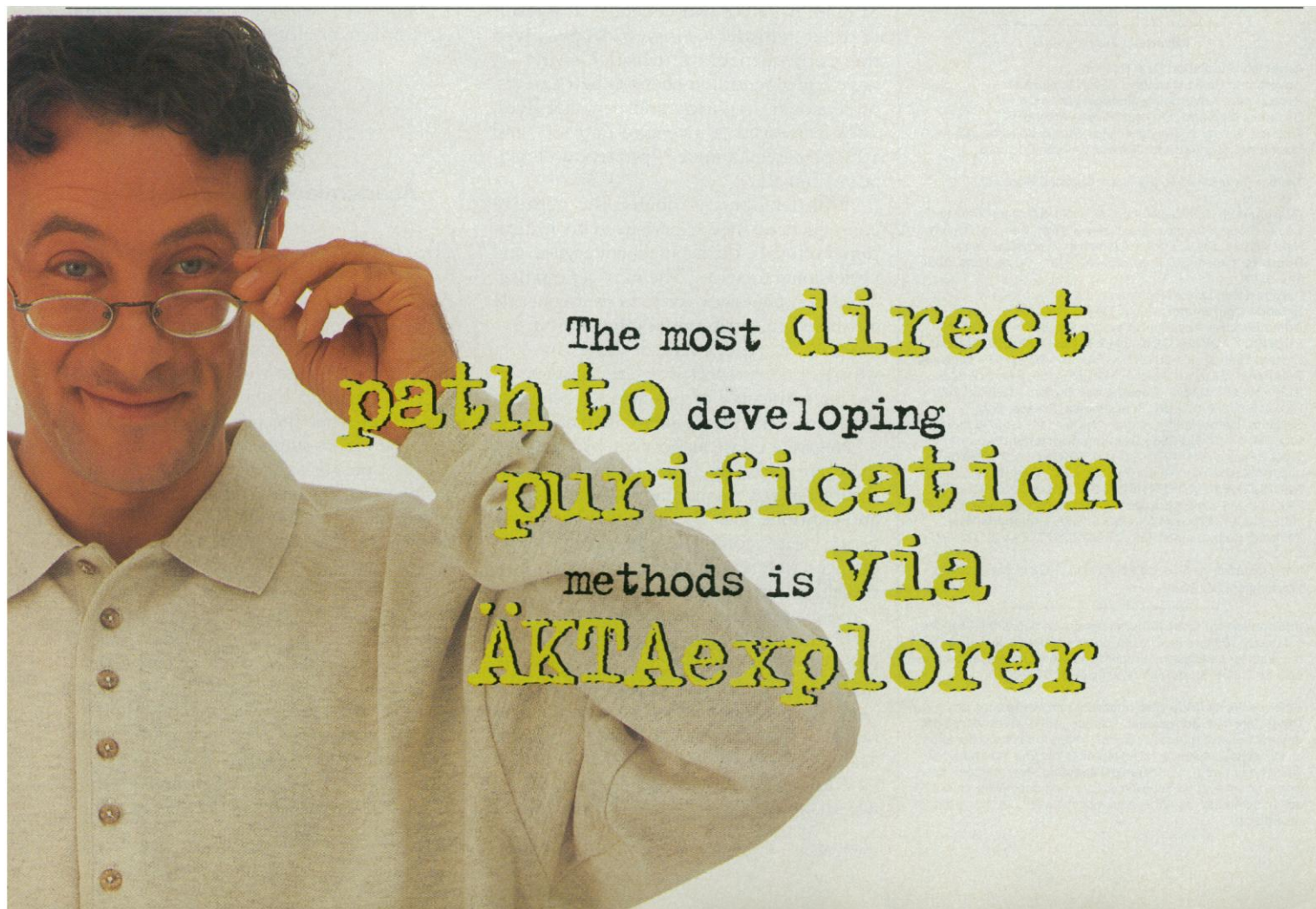
Eliot Marshall's News & Comment article, "Policy on DNA research troubles tissue bankers" (26 Jan., p. 440) describes an ongoing debate about researchers' use of previously collected tissue samples for research about which patients were not advised or asked for consent (1, 2). In one such case, a pathologist tested a woman's surgical sample for the breast cancer gene, then called her, and told her she had the gene. The woman thus received psychologically troubling and financially risky information she did not want. She and her children will likely be denied health-care insurance (or at least coverage for breast, coronary, and prostate cancer) on the basis of this information (K. L. Hudson *et al.*, Policy Forums, 20 Oct., p. 391).

The article makes it appear that new, burdensome regulations are being proposed that would require the patient's consent before research is done on his or her sample. In fact, federal regulations already in force generally require consent when the patient will be identifiable. These existing regulations are being ignored, sometimes to the detriment of patients.

Marshall's article also makes it appear that research on a set of samples collected

by the Centers for Disease Control and Prevention (CDC) has been delayed because of frivolous concerns by ethicists. Not mentioned is the profound dilemma that the CDC has found itself in. The initial collection of samples by the CDC was not, as Marshall says, "to create a repository for research on genetic diseases." Rather it was to monitor the state of national health and nutrition by testing people on a limited number of health indicators such as blood pressure, cholesterol level, and so forth. In its original consent form, CDC promised all the research participants that they would be recontacted with abnormal results. What happens now, though, if researchers use the CDC samples to study the prevalence of the Huntington's gene or a gene linked to male sexual preference and they reveal this information to the person? This may not be information the person wants to have, given that, for example, fewer than 15% of at-risk individuals seek screening for Huntington's disease (3). And what about those people who are given unasked for genetic information that is erroneous because the research tests have not been perfected—and take drastic action on the basis of the results?

Research in this country is based on the idea of voluntary, informed consent; it is



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not a matter of conscription. Patients should be asked in advance of a sample being taken whether they are willing to have it used for genetic research or whether, if the researcher is planning to recontact them with results, they want to refuse that contact. This is unlikely to, as some pathologists have suggested, "totally cripple" research in the country. In institutions that already ask for consent for genetics research, it is seldom, if ever, refused.

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#### References

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2. Storage of Genetic Material Committee, American College of Medical Genetics, *Am. J. Hum. Genet.* **57**, 1499 (1995).
3. M. Bloch, M. Fahy, S. Fox, M. R. Hayden, *Am. J. Med. Genet.* **32**, 217 (1989).



#### Access to the Internet

I would like to comment on the editorial "An enhanced perspective" by Floyd E. Bloom (9 Feb., p. 741). Issues of equity

should be taken into account in education and scientific research in general. It was stated in a CNN broadcast on 16 February that students from low-income households have fewer opportunities to have access to the Internet in schools. Responding to that report, President Clinton announced that inequitable use or access to the information highway in schools should be addressed.

The "resources required to provide" the enhanced information network are enormous. Some are able to afford the infrastructures for such a network to be enhanced. However, in some low-income communities, and in low-income countries, people may live far away from the information highway. More than 60 million people worldwide, most of them in high-income countries, currently use the Internet. Without improving access, the enhanced perspectives could further widen disparities between the privileged and the underprivileged.

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*Editor's note:* We would be interested in a wider expression of opinions on this matter.

#### From Plants to Mammals

We read with interest Rachel Nowak's piece on the American Society of Human Genetics meeting describing the dominant negative mutation in myotonic dystrophy that occurs in RNA (Research News, 17 Nov., p. 1120). The idea that an aberrant RNA (truncated, improperly processed, or overly abundant) can also "knock out" normal copies of the RNA is not, however, entirely new. This possibility has been recognized by plant molecular biologists studying the phenomena sense suppression (1) and RNA-mediated virus resistance (2) in transgenic plants. An examination of the plant literature on these topics [for reviews, see (3)] might be helpful to researchers identifying similar and possibly related processes in mammals.

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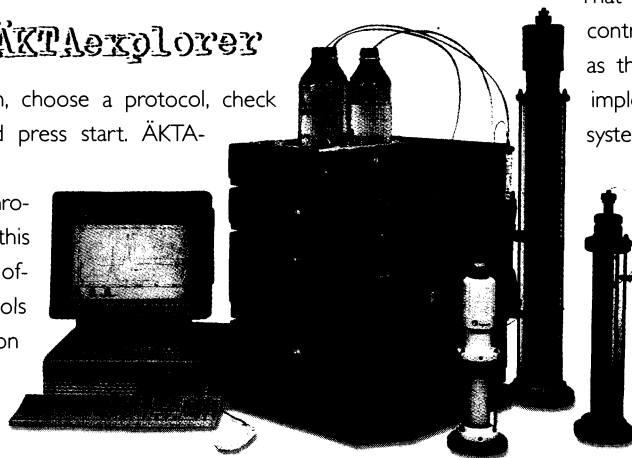
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