oncogenic viruses, comparative biology of normal and cancerous cells, and genetic determinants of cancer.

An NCI diet, nutrition, and cancer program has been established to sponsor research and collect information on the role of diet and nutrition in the etiology of cancer and in the treatment, long-term management, and rehabilitation of the cancer patient. Some of the areas involved to date in NCI-supported nutrition research are carcinogenesis, epidemiology, and chemotherapy.

Other opportunities to increase knowledge of cancer have expanded as a result of accelerated exploration in areas such as cell biology, molecular biology, virology, and immunology. For example, results of basic cellular research are providing clinical research investigators clues to more effective treatment of cancer patients with improved chemotherapy regimens and the emerging modality of immunotherapy.

At the level of fundamental research, which has been receiving substantial NCI support, it is often impossible to distinguish advances in knowledge that will eventually be used in cancer from those that will help other areas. Information from basic biomedical research supported

by NCI increases the total accrued knowledge and may well assist research on other diseases. Similarly, important fallout for cancer derives from research in other areas, for the fundamental processes of life and growth are inexorably linked with cancer.

Health-oriented research requires the continued advice and collaborative endeavors of scientists of all the basic laboratory and clinical disciplines. The National Cancer Program will affect all of us, scientifically and personally. NCI welcomes comments and counsel from the scientific community. It will continue the productive biomedical research efforts whose goal is not only new ideas and new knowledge but a better quality of life.

### Summary

Fundamental research is supported to obtain the knowledge lacking about the basic mechanisms about cancer. The NCI supports basic research through grants, contracts, and in-house activities. In FY 1974, the increasing amounts obligated for basic research within the various parts of the total NCI program accounted for more than half of the total budget. The high quality of research is assured through use of peer review of applications and support of research training. The NCI has consistently backed the cause of adequate budgets for biomedical research for all the NIH institutes.

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### **NEWS AND COMMENT**

# Genetic Screening: NAS Recommends **Proceeding with Caution**

Genetic screening is a good thing-but only in carefully controlled circumstances, according to a committee of the National Academy of Sciences (NAS). After a  $2^{1/2}$ -year analysis of the state of the art and the politics of the situation, the committee concluded that it is not yet time to recommend community, mass screening programs. The committee's feelings on this point, according to chairman Barton Childs of the Johns Hopkins University School of Medicine, were not accurately stated in a NAS press release that said genetic screening programs should be made available nationwide "as a matter of public health policy."

At a 23 June press conference on the committee's report\*, Childs stressed the

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fact that genetic screening of asymptomatic individuals should still be considered an experimental procedure in need of considerable evaluation of its potential benefits versus its inherent risks. Nevertheless, the committee strongly endorsed the continuation and expansion of genetic screening in the proper setting. What it opposes is the kind of mass screening program in which groups of citizens are virtually recruited off the streets to have their genes checked.

Genetic screening used to be a rather uncommon medical procedure that touched the lives of relatively few families. Even a decade ago, there were not many genetic disorders that could be detected in individuals who had no symptoms of disease. Moreover, most of the disorders that could be picked up were identifiable only by techniques that were difficult to carry out and were considered highly experimental.

Then, in the 1960's, it became possible

to screen newborn babies for phenylketonuria (PKU), an inborn error of metabolism that leads to severe mental retardation if not treated early. PKU had a lot to recommend it as a candidate for mass screening. The methods for detecting it were simple, requiring only a small sample of blood taken from the infant at birth. It was not very expensive. It presumably harmed no one. And, best of all, if a PKU baby were detected, he could be spared mental retardation by being fed the correct foods. If foods containing phenylalanine, such as bread, were kept out of the diet, brain development would not be significantly impaired. (The difficulties of keeping a young child on a low-phenylalanine diet cannot be overestimated.)

PKU screening seemed like a very reasonable thing to do, and eager geneticists went to their legislators seeking state help in setting up mass screening programs. The legislators in most states readily complied; since 1963, the NAS says, 43 states have passed laws requiring or recommending PKU screening in newborns.

Looking at the PKU programs with hindsight, the NAS committee is among many groups that have come to the realization that everything was not as right as it first seemed. For one thing, it turns out

<sup>\*</sup>Genetic Screening—Programs, Principles and Re-search is a report of the Committee for the Study of In-born Errors of Metabolism. A limited number of cop-ies are available without charge from the National Academy of Sciences, 2101 Constitution Avenue, NW, Washington, D.C. 20418.

that the early techniques for detecting PKU showed a disturbingly high rate of false positives. As a result, a number of infants who did not have PKU at all were put on phenylalanine-restricted diets which can be harmful to normal growth because this amino acid is essential to brain development.

Not long after PKU screening became the norm in most states, researchers perfected techniques for the mass screening of sickle cell anemia and the sickle cell trait. This scientific advance occurred at a time when civil rights were very much on everyone's mind, and the inclination to screen all black children and young people was too strong to resist. As with PKU, some state and local jurisdictions made sickle cell screening mandatory.

The history of sickle cell screening teaches profound lessons about the dangers of rushing headlong into any kind of program, however well intentioned, involving people's genes. Frequently individuals who were told they carried the sickle cell trait were confused by the information. Some felt stigmatized by the knowledge and believed they carried a "bad gene" that, if passed on to their children, would cause sickle cell anemia. Insurance companies associated the relatively harmless sickle cell trait with the active diseasesickle cell anemia-and refused to insure trait carriers at the usual rates. The problems surrounding mass screening for sickle cell disorders were compounded by the fact that there is no cure for the disease. It was very much a case of giving people complicated and frightening information about which they could do very little.

Bearing the PKU and sickle cell screening experiences in mind, the NAS committee decided not to recommend any mass screening (except for PKU for which the problems seem to have been ironed out). Instead, it set forth detailed guidelines on how to go about setting up and, importantly, evaluating new programs in genetic screening. (These days, reports of newly developed techniques for detecting genetic disorders appear so frequently as to be commonplace.)

The committee is emphatically opposed to any laws or regulations that make screening mandatory and would implicitly like to see existing PKU legislation modified accordingly. It would like to see screening, as it matures, become a part of general medical practice-an activity carried out by a physician in his office, not by a health worker in a school gymnasium or church auditorium. And it believes screening should be carried out only when high standards for scientific accuracy and patient follow-up are met. The committee is aware of the importance of giving individuals thorough and understandable information before and after they have been screened, but it also recognizes the pitfalls that exist in this regard. (Several studies have indicated, to the disheartenment of geneticists, that, even after careful counseling and oral and written information have been made available, people can still become confused about what they have been told about their genes.)

Perhaps one of the more significant of the NAS recommendations about genetic screening is one dealing with public involvement in setting up programs. Noting that a program that might be acceptable to one community might be offensive to another, Childs and his committee call for a good deal of citizen participation. Following the current vogue for establishing commissions, the committee recommends that commissions or "screening authorities," that would be composed of researchers and lay members, review all proposed new screening programs to determine in advance a number of questions, among them the following:

• Is the public interested in and prepared to accept screening for the disease in question?

• Will public facilities, such as laboratories, be needed? If so, what will the cost be?

• Will the public need to be educated about the nature and consequences of a particular program? If so, how?

• Is the proposed screen scientifically accurate? What treatment can be offered to persons identified as having the screened-for condition? Are the treatments effective?

It is the committee's opinion that, even if all of the potential problems-legal, ethical, and medical-can be worked out in pilot screening programs, a decision about adopting a large-scale screen remains in the domain of the screening authority which has the option of deciding against it. "This decision," the NAS report says, "will be determined in part by the successes or failures observed in the pretest, but also in part by those evidences of public and medical acceptance and sense of need that were considered in the beginning." Thus, even the conservative NAS is now going along with the idea that just because the research community is interested in pursuing some idea is not reason enough to go ahead with it. One needs the consent of the community.

-BARBARA J. CULLITON

## Futurism: Gaining a Toehold in Public Policy

We cannot go on letting the future just happen to us.—EDWARD CORNISH, president of the World Future Society

Grand visions of the future issue easily from politicians and policy-makers. But systematic strategies for getting there from here are another matter altogether. That is what applied futurism is all about. Futurism (or "futuristics," for those who want to make it into a science) has flourished for years in think tanks; in recent years this discipline—it would be more accurate perhaps to call it a mode of thought—has been emerging from the hothouse academic environment into the realm of public policy.

This was evident at the Second General Assembly of the 9-year-old World Future Society (WFS), held in Washington, D.C.,

last month. The meeting, intellectually dominated by the likes of Herman Kahn, Daniel Bell, and Alvin Toffler, was heavily attended-by planners, philosophers, professors, small businessmen, computer programmers, and the generally curious. According to WFS followers, this year's assembly differed from the first, held in 1971, chiefly in that the proportion of utopians and "characters" is declining (there was no astrology booth this year). Moreover, there was higher participation on the part of the normal, stodgy people, the bureaucrats, and people responsible for injecting thought into government-a reflection of futurism's growing appeal in various crannies of the federal government.

Applied futurism is a combination of planning and prognostication. As a discipline it differs from long-range forecasting in a particular field, or statistical