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Reply to Lippman

To the Editor:

Dr. Abby Lippman's eloquent letter underscores the complexity of the relationship between medical genetics and public health. She describes the interlocking web of scientific, ethical, philosophical, economic, and political factors that impact on public health planning and decision making.

Dr. Lippman's comments provide needed insight into the process by which public health personnel determine and achieve their goals. She discusses competing needs and the possibility of a variety of approaches which could "be taken to insure . . . collective health." Program directors are compelled to set priorities which will improve the health of those citizens served by their municipality, state, or region.

It is time that medical genetic programs be included in these deliberations. Cunningham and Kizer's (1990) cogent paper identifies problems in communication between public health personnel and members of the medical genetics community. In their efforts to determine the response of state health department personnel to The American Society of Human Genetic's policy statements on maternal serum alpha-fetoprotein screening, the authors found lack of information, lack of interest, and inertia.

Their findings must be addressed. As more and more genetic programs such as cystic fibrosis carrier testing develop, it will be increasingly important to work closely together. The involvement of public health professionals permits wide public participation, including opportunities for meaningful debate. This interaction should be encouraged particularly at a time when colossal cuts in state and federal spending will further increase tensions between competing programs and sharply curtail programmatic goals and objectives. One of our profession's aims should be the establishment of close working relationships with our colleagues in public health, which will be to our mutual benefit.

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Reference

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Update on Maternal Serum Alpha-Fetoprotein Screening

To the Editor:

In 1987, the American Society of Human Genetics (ASHG) published a policy statement for maternal serum alpha-fetoprotein (MSAFP) screening programs and quality control for laboratories performing MSAFP and amniotic-fluid AFP assays (American Society of Human Genetics 1987). This was updated in 1989 (Garver 1989). A recent article by Cunningham and Kizer (1990) reviewed the impact that these policy statements have had on state public-health agencies, with respect to regulation and provisions of MSAFP screening in their jurisdictions.

The authors distributed one questionnaire in 1987 and another in 1990 to all state health officers and to all state maternal/child-health laboratory and public-health-laboratory directors. Speaking as the chairman of the two ad hoc committees that drafted the policy statements for the ASHG, I find it distressing that (1) despite the wide dissemination of this document in 1987, 22 of the states indicated that they were unaware of it and (2) in 1990, 16 states reported ignorance of the ASHG policy statement. Drs. Cunningham and Kizer performed a worthwhile service in calling our attention to how difficult it is to disseminate ideas into the community.

One statement by Cunningham and Kizer (1990, p. 901), I believe, needs clarification. In their text they state that, "by its very nature, MSAFP testing is the kind of program that lends itself to a state or regional public-health approach." Further on in the same paragraph of their discussion, they state that, "for these reasons, experts have uniformly concurred with ASHG in recommending a centrally organized and regulated approach to protect against those abuses of the technology that have occurred in an uncontrolled environment." It was not the intent of the policy statement from the ASHG to in any way endorse a complete

full-service state program for MSAFP screening, in which the state would provide clinical services such as counseling and follow-up for abnormal MSAFP results.

Several points are stressed in the ASHG policy statement: (1) that MSAFP screening is a screening test and is not diagnostic, (2) that MSAFP screening is becoming part of routine obstetrical care, (3) that MSAFP screening should be voluntary, (4) that MSAFP screening should only be undertaken in conjunction with a competent laboratory and comprehensive program, (5) that the ASHG strongly supports regulations for quality control of any laboratory involved in carrying out MSAFP screening and/or amniotic-fluid AFP determinations, and (6) that there should be a great input for physician-patient and other health-professional education. The flavor of the policy statement was that the clinical interpretations of MSAFP testing be given by primary-care physicians, genetic counselors, or appropriate clinics, so that a one-to-one relationship could be maintained between the physician and patient. The guidelines strongly stressed that the role of the state was to assure firm quality-control guidelines for any laboratory doing MSAFP or any of the other tests related to this screening program.

Speaking as a medical geneticist, I would like to present some of the concerns I have when either a federal or a state government assumes the role of dispenser of and controller of genetic information. As George Santayana so succinctly put it, "those who cannot remember the past are condemned to repeat it." The intrusion of government into genetics has led to some disastrous results, as can be seen by evaluating the American eugenics movement, in which the federal government (in the Johnson Restrictive Immigration Act of 1924) and the state governments in involuntary-sterilization laws of the first part of the 20th century) grossly misused pseudoscientific information concerning racial traits and the worth of an individual, policies which resulted in injustices and in restriction of freedom.

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Ethics of a Genetic Program for Myotonic Dystrophy

To the Editor:

In their recent letter on the ethics of cystic fibrosis screening (CF), De Braekeleer and Mélançon (1990) tangentially raised the subject of screening for myotonic dystrophy (MD) in the Saguenay-Lac-St-Jean (SLSJ) region. This formed the basis of their position against CF screening, as "a mistake which could be detrimental to the individuals and the populations."

This reference to "screening" and "detriments" reflects on the ethics of the activities of the Quebec Network for Genetic Medicine (QNGM), which is known internationally and which represents most of the activities in genetic epidemiology in Quebec. I would like to raise two issues that may be of importance to geneticists as we start to apply to populations the knowledge emanating from human genome mapping. The first issue relates to specific terms for specific activities and to the ethics expected for each; the second issue questions the role of bioethicists in genetic services.

During 1977–82 in the SLSJ region there were five episodes of clinical case finding for MD that were prompted by neurologists and local physicians impressed by the apparent high prevalence of patients. This endeavor was sponsored by a local nonprofit corporation with representation from the public, social, scientific, and medical communities (CORAMH). There was extensive regional media coverage and discussion on this supposed "screening," so much so that in 1983 the Ministry of Health of Quebec mandated