

February 27, 1983

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Mr. Emilio Daddario
2524 Q Street, N.W.
Washington, D.C. 20007

... OTA

Dear Mr. Daddario,

I have in mind a more detailed discussion that I will send you in some few weeks about the problematics of a technology assessment of prenatal screening. Meantime, however, I thought I should send you some calculations that John O'Brien has made for the specific case of Tay-Sachs disease. You will see that he reaches a conclusion that population screening and selective abortion would be quite cost effective for the Jewish population, with a benefit cost ratio of 2.6 whereas it would not be for the population at large with a corresponding ratio of only .03.

I should point out that this is a rather special case in which a deleterious gene is concentrated within a particular group and where a serum assay enables one to find the rather infrequent carriers. You will see that a very large part of the total cost would be extended in the serum assays and that these are relatively unproductive except for the concentrated population group in this case the Ashkenazi Jews. One must also point out that the costs and benefits are calculated in strictly medical terms and that such intangibles as a) the non-monetary impact of the damaged child on the parents and the family and b) the overall cultural consequences of medically encouraged abortion and the intangible costs of that procedure are neither of them gone into. This, of course, epitomizes the dilemma you will face many times in technology assessments, the extra-economic values. I have gone into this rather superficially in another paper that I am enclosing on "Radiobiology and the Cost of Life". A recent paper by Michan develops a basically similar line of argument rather further.

I was very warm to the idea of an intensive but low profile study of these questions. Conversely I was rather less enthusiastic when Larry Horowitz from Senator Kennedy's staff called me yesterday to ask for public testimony in connection with the Senator's current hearings on the abuses of human subjects in medical experimentation. I am certainly not going to defend some of the cruelties that have been promulgated in the name of (bad) medicine but these hearings hardly promise to offer the most conducive background for longer range considerations of biosocial policy nor of the defense against the administration's attack on the budgeting for research which is one of our most immediate survival issues.

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Jewish Birth.
O'Brien / TASHS-1983/23
for Bio category.

See Section 47 f/b

cautious: no prenatal diagnosis.

also → PHOEBS re contact in NRDC

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I will be in touch with you further. Meantime, if I could have some psychological reinforcement from you giving some more detail about what you might look for from me and how you might wish me to bring in the colleagues whose names I mentioned to you (O'Brien, Motulsky, Marge Shaw) I might be assured that I am heading on the right track.

You probably are aware that Dr. Barton Childs, of Johns Hopkins, is chairing an Academy committee on genetic screening. While I understand that its major emphasis at present is intended to be on post-natal screening for situations like PKU I suspect it would not be difficult to get Barton to broaden his emphasis with some minimal encouragement from you or from me. Let me know your pleasure about trying to pursue that.

Sincerely yours,

Joshua Lederberg
Professor of Genetics

JL/rr
Enclosure