



CHARTER

NATIONAL ADVISORY COUNCIL FOR HUMAN GENOME RESEARCH

COMMITTEE'S OFFICIAL DESIGNATION

National Advisory Council for Human Genome Research

AUTHORITY

Required by 42 U.S.C. 284a, section 406 of the Public Health Service (PHS) Act, as amended. The National Advisory Council for Human Genome Research (Council) is governed by the provisions of the Federal Advisory Committee Act, as amended (5 U.S.C. §§ 1001-1014).

OBJECTIVES AND SCOPE OF ACTIVITIES

The Council will advise, assist, consult with, and make recommendations to the Secretary of Health and Human Services (Secretary) and the Director, National Human Genome Research Institute (NHGRI, also referred to as Institute) on matters related to the activities carried out by and through the Institute and the policies respecting these activities.

DESCRIPTION OF DUTIES

The Council may recommend to the Secretary, in accordance with section 231 of the PHS Act, as amended, acceptance of conditional gifts for study, investigation, or research on the development of basis to understanding genomic research for the acquisitions of grounds, or for the construction, equipping, of maintenance of facilities for the Institute.

The Council may review applications for grants and cooperative agreements for research and training and recommend approval of applications for projects which show promise of making valuable contributions to human knowledge; may review any grant, contract, or cooperative agreement proposed to be made or entered into by the Institute; may collect, by correspondence or by personal investigation, information as to studies which are being carried on in the United States or any other country as to the diseases, disorders, or other aspects of human health with respect to which the Institute was established and, with the approval of the Director, NHGRI, make available such information through appropriate publications for the benefit of public and private health entities, health professions personnel and scientists, and for the information of the general public.

The Council will prepare triennial reports describing the manner in which the Institute has complied with section 492B of the PHS Act, as amended, which sets forth requirements addressing the inclusion of women and members of minority groups as subjects in clinical research conducted or supported by the National Institutes of Health (NIH). Each report shall be submitted to the Director, NHGRI, for inclusion in the triennial report submitted to Congress by the Director, NIH, pursuant to section 403 of the PHS Act, as amended. Each triennial report prepared by the Council

shall include each of the following:

1. The number of women included as subjects, and the proportion of subjects that are women, in any project of clinical research conducted during the applicable reporting period, disaggregated by categories of research area, condition, or disease, and accounting for single-sex studies.
2. The number of members of minority groups included as subjects, and the proportion of subjects that are members of minority groups, in any project of clinical research conducted during the applicable reporting period, disaggregated by categories of research area, condition, or disease, and accounting for single-race and single-ethnicity studies.
3. For the applicable reporting period, the number of projects of clinical research that include women and members of minority groups and that—
 - (a) have been completed during such reporting period; and
 - (b) are being carried out during such reporting period and have not been completed.
4. The number of studies completed during the applicable reporting period for which reporting has been submitted in accordance with section 492B(c)(2)(A) of the PHS Act, as amended.

AGENCY OR OFFICIAL TO WHOM THE COMMITTEE REPORTS

The Council will advise the Secretary and the Director, NHGRI.

SUPPORT

Management and support services will be provided by the Division of Extramural Operation (NHGRI).

ESTIMATED ANNUAL OPERATING COSTS AND STAFF YEARS

The estimated annual cost for operating the Council, including compensation and travel expenses for members, but excluding staff support, is \$54,846. The estimated annual person-years of staff support required is 0.6 at an estimated annual cost of \$89,472.

DESIGNATED FEDERAL OFFICER

The Director, NHGRI, will assign a full-time or permanent part-time NHGRI employee to serve as the Designated Federal Officer (DFO) of the Council. In the event that the DFO cannot fulfill the assigned duties of the Council, one or more full-time or permanent part-time NHGRI employees will be assigned as DFO and carry out these duties on a temporary basis.

The DFO will approve all of the Council's and subcommittees' meetings, prepare and approve all meeting agendas, attend all Council and subcommittee meetings, adjourn any meeting when it is

determined to be in the public interest, and chair meetings when directed to do so by the official to whom the committee reports.

The Director, NHGRI shall designate a member of the staff of the Institute to serve as the Executive Secretary of the Council. The staff member assigned to serve as DFO will also be assigned to serve as the Executive Secretary

ESTIMATED NUMBER AND FREQUENCY OF MEETINGS

Meetings of the full Council will be held at the call of the Chair (with the DFO's approval) or upon request of the Director, NHGRI, not less than three times within a fiscal year. Meetings will be open to the public except as determined by the Secretary at the request of the DFO in accordance with 5 U.S.C. 552b(c) and 41 C.F.R. 102-3.155 including specifying the specific exception(s) that justifies closure. Notice of all meetings will be given to the public. In the event a portion of a meeting is closed to the public, as determined by the Secretary, in accordance with the Government in the Sunshine Act (5 U.S.C. 552b(c)) and the Federal Advisory Committee Act, an annual report of closed or partially-closed meetings will be prepared which will contain, at a minimum, a list of members and their business addresses, the Council's functions, dates and places of meetings, and a summary of the Council's activities and recommendations made during the fiscal year.

DURATION

Continuing.

TERMINATION

Unless renewed by appropriate action, prior to its expiration, the Charter for the National Advisory Council for Human Genome Research will expire two years from the date the charter is filed.

MEMBERSHIP AND DESIGNATION

The Council will consist of not more than 18 members appointed by the Secretary (appointed members) and at least 5 nonvoting ex officio members. The nonvoting ex officio members will include the Secretary; the Director, NIH; the Director, NHGRI; the Under Secretary for Health of the Department of Veterans Affairs; the Assistant Secretary of Defense for Health Affairs (or their designees); and any additional officers or employees of the United States as the Secretary determines necessary for the Council to effectively carry out its functions. Appointed members must be eligible to serve as Special Government Employees (SGEs) and will serve as SGEs, as defined by 18 U.S.C. § 202. Two-thirds of the appointed members will be selected from among the leading representatives of the health and scientific disciplines (including not less than 2 individuals who are leaders in the fields of public health and the behavioral and social sciences) relevant to the activities of the NHGRI. One-third of the appointed members will be appointed by the Secretary from the general public and will include leaders in fields of public policy, law, health policy, economics, and management. A quorum for the conduct of business by the full Council will consist of a majority of currently appointed members.



NOTICE OF RENEWAL

NATIONAL ADVISORY COUNCIL FOR HUMAN GENOME RESEARCH

The National Advisory Council for Human Genome Research was established by statute and has functions that are of a continuing nature so that its duration is not governed by section 1013(a) of the Federal Advisory Committee Act but is otherwise provided for by law. The National Advisory Council for Human Genome Research is hereby renewed in accordance with section 1013(b)(2) of that Act.

Date

Lawrence A.
Tabak -S

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Lawrence A. Tabak -S
Date: 2024.05.02
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Principal Deputy Director, NIH