



## **CHARTER MUSCULAR DYSTROPHY COORDINATING COMMITTEE**

### **AUTHORITY**

Required by 42 U.S.C. 283g, Section 404E of the Public Health Service Act, as amended. The Muscular Dystrophy Coordinating Committee (Committee) is governed by the provisions of the Federal Advisory Committee Act, as amended (5 U.S.C. app.), which sets forth standards for the formation and use of advisory committees.

### **OBJECTIVES AND SCOPE OF ACTIVITIES**

The Committee will coordinate research activities across the National Institutes of Health (NIH) and with other Federal health programs and activities relating to the various forms of muscular dystrophy, including Duchenne, Becker, congenital muscular dystrophy, limb-girdle muscular dystrophy, myotonic, facioscapulohumeral muscular dystrophy and other forms of muscular dystrophy.

### **DESCRIPTION OF DUTIES**

The Committee will develop a plan for conducting and supporting research and education on muscular dystrophy through the national research institutes and will periodically review and revise the plan. The plan will (a) provide for a broad range of research and education activities relating to biomedical, epidemiological, psychosocial, and rehabilitative issues, including studies of the impact of these diseases in rural and underserved communities; (b) identify priorities among the programs and activities of the NIH regarding these diseases; and (c) reflect input from a broad range of scientists, patients, and advocacy groups. In developing this plan, the Committee may evaluate the potential need to enhance the clinical research infrastructure required to test emerging therapies for the various forms of muscular dystrophy by prioritizing achievement of the goals related to this topic.

### **AGENCY OR OFFICIAL TO WHOM THE COMMITTEE REPORTS**

The Committee will advise, assist, consult with, and make recommendations to the Secretary of Health and Human Services (Secretary), to the Director, NIH, and the Director, National Institute of Neurological Disorders and Stroke (NINDS).

### **SUPPORT**

Management and support services will be provided by the Division of Extramural Research, NINDS.

### **ESTIMATED ANNUAL OPERATING COST AND STAFF YEARS**

The estimated annual cost for operating the Committee, including compensation and travel expenses for members, but excluding staff support, is \$27,960. The estimated annual person-years of staff support required is 0.3 at an estimated annual cost of \$84,533.

### **DESIGNATED FEDERAL OFFICER**

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

The DFO will approve or call all of the Committee's and subcommittees' meetings, prepare and approve all meeting agendas, attend all Committee 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 Director, NIH, or the Director, NINDS.

### **ESTIMATED NUMBER AND FREQUENCY OF MEETINGS**

Meetings of the full Committee will be held no fewer than two times per calendar year. Meetings will be open to the public except as determined otherwise by the Secretary in accordance with subsection (c) of section 552b of Title 5 U.S.C. 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, a report will be prepared which will contain, as a minimum, a list of members and their business addresses, the Committee's functions, dates and places of meetings, and a summary of the Committee's activities and recommendations made during the fiscal year. A copy of the report will be provided to the Department Committee Management Officer.

### **DURATION**

Continuing.

### **TERMINATION**

Unless renewed by appropriate action, the Muscular Dystrophy Coordinating Committee will terminate two years from the date the charter is filed.

### **MEMBERSHIP AND DESIGNATION**

The Committee will consist of not more than 18 members, including the Chair, appointed by the Secretary. Two-thirds of the members will represent governmental agencies, including the directors or their designees of each of the national research institutes involved in research with respect to muscular dystrophy and representatives of all other Federal departments and agencies whose programs involve health functions or responsibilities relevant to these diseases, including the Centers for Disease Control and Prevention, the Health Resources and Services Administration, the Food and Drug Administration, the Administration for Community Living, and representatives of other governmental agencies including

the Department of Education and the Social Security Administration. One-third of the members will represent the public, including a broad cross section of persons affected with muscular dystrophies, including parents or legal guardians, affected individuals, researchers, and clinicians.

Public members will be invited to serve for a term of three years and may serve for an unlimited number of terms if reappointed. Terms of more than two years are contingent upon the renewal of the Committee by appropriate action prior to its termination. Members may serve after the expiration of their terms until their successors have taken office.

The Chair of the Committee will serve as the principal advisor to the Secretary, the Assistant Secretary for Health, and the Director of NIH, and will provide advice to the Director of the Centers for Disease Control and Prevention, the Commissioner of the Food and Drug Administration, and to the heads of other relevant agencies. The Committee will select the Chair for a term not to exceed two years. The Chair of the Committee will be appointed by, and be directly responsible to, the Secretary. A quorum for the conduct of business by the full Committee will consist of a majority of currently appointed members.

### **SUBCOMMITTEES**

As necessary, subcommittees and ad hoc working groups may be established by the DFO within the Committee's jurisdiction. The advice/recommendations of a subcommittee/working group must be deliberated by the parent advisory committee. A subcommittee may not report directly to a Federal official unless there is statutory authority to do so.

Subcommittee membership may be drawn in whole or in part from the parent advisory committee. All subcommittee members may vote on subcommittee actions and all subcommittee members count towards the quorum for a subcommittee meeting. Ad hoc consultants do not count towards the quorum and may not vote. A quorum for a subcommittee will be three members. The Department Committee Management Officer will be notified upon establishment of each standing subcommittee and will be provided information on its name, membership, function, and estimated frequency of meetings.

### **RECORDKEEPING**

Meetings of the Committee and its subcommittees will be conducted according to the Federal Advisory Committee Act, other applicable laws and Departmental policies. Committee and subcommittee records will be handled in accordance with General Records Schedule 6.2, Federal Advisory Committee Records, or other approved agency records disposition schedule. These records will be available for public inspection and copying, subject to the Freedom of Information Act, 5 U.S.C. 552.

### **FILING DATE**

August 15, 2018

### **APPROVED:**

7/30/2018

Date

Dr. Francis Collins, M.D., Ph.D.

Director, NIH