

POLICIES AND PROCEDURES FOR WORKING WITH A MEDICAL ADVISORY BOARD

Produced by the National Organization for Rare Disorders (NORD®)

THE MEDICAL ADVISORY BOARD

Purpose: The purpose of the Medical Advisory Board is to offer expertise on scientific developments, to provide insights on the needs of the DISEASE STATE(S)'s population, and to assure that [ORGANIZATION NAME]'s policies, research, grants, marketing, communications, and publications meet the highest standards of scientific rigor and accuracy.

The volunteer Medical Advisory Board's activities are to be exclusively scientific and educational, including, but not limited to:

- a. Upholding the values and pursuing the mission of [ORGANIZATION NAME];
- b. Reviewing the strategic plan, agenda, and supporting materials prior to board meetings;
- c. Reviewing and revising any materials containing scientific information to be made available to the public, including scientific information disseminated online and in print;
- d. Working in sub-committees to achieve goals related to research, marketing, drug development, publications, funding applications and other areas as necessary;
- e. Assisting in identification and acquisition of external funding sources including, but not limited to, grants and sponsorships;
- f. Ensuring that funding for research is awarded on the basis of scientific merit, originality and contribution to the area of DISEASE STATE(S);
- g. Accumulating and disseminating scientific information about DISEASE STATE(S);
- h. Attending in-person or telephone conference call meetings to discuss medical updates and goals for the upcoming year;
- i. Providing recommendations for grants, events and research in the best interest of the organization and DISEASE STATE(S) patients.

In addition to these activities, the Medical Advisory Board must adhere to the following:

- j. A three-year term of office (fiscal year June – May) upon appointment by the Medical Advisory Board, with possible reappointment following the end of their term for another term, capped at three consecutive terms.
- k. Approval by the Board of Directors for any activities performed on behalf of the organization, which are property of the organization, prior to public dissemination.
- l. Actions performed should be in the best interest of the organization and cannot personally profit any member(s) involved in the review and approval of the activity.

CONFLICT OF INTEREST POLICY

No member of the [ORGANIZATION NAME] Medical Advisory Board or any of its committees shall derive any personal profit or gain, directly or indirectly, by reason of his or her participation on the Medical Advisory Board. Each individual shall disclose to [ORGANIZATION NAME] any personal or financial interest which he or she may have in any matter pending before [ORGANIZATION NAME], and shall refrain from participation in any discussion and decision on such matter. Any member of the [ORGANIZATION NAME] Medical Advisory Board shall agree and adhere to the [ORGANIZATION NAME] Conflict of Interest policies that also govern the Board of Directors.