

## THE SNYDER-ROBINSON FOUNDATION MEDICAL AND SCIENTIFIC ADVISORY BOARD POLICIES AND PROCEDURES

Effective date: December 1, 2019

**Purpose:** The purpose of the Medical Advisory Board is to offer expertise on scientific developments, to provide insights on the needs of the Snyder-Robinson Syndrome population, and to assure that The Snyder-Robinson Foundation's policies, research, grants, marketing, communications, and publications meet the highest standards of scientific rigor and accuracy. The volunteer Medical and Scientific 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 The Snyder-Robinson Foundation;
- 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 Snyder-Robinson Syndrome;
- q) Accumulating and disseminating scientific information about Snyder-Robinson Syndrome:
- 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 Snyder-Robinson Syndrome patients.

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

- a) A three-year term of office commencing when the Board of Directors confirms the member's appointment by the Director of Research. Possible reappointment following the end of their term will be capped at three consecutive terms (nine years).
- b) 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.
- c) 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 Medical and Scientific 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 and Scientific Advisory Board. Each individual shall disclose in writing, which may be electronic, to the Director of Research any personal or financial interest, which he or she may have in any matter pending before the Snyder-Robinson Foundation, and shall refrain from participation in any discussion and decision on such matter. Any member of the Snyder-Robinson Foundation Medical and Scientific Advisory Board shall agree and adhere to the Snyder-Robinson Foundation Conflict of Interest policies that also govern the Board of Directors.