

CMTA-STAR ADVISORY BOARD

Confidentiality and Conflict of Interest Policy

Purpose

1. Advancing the research mission of the Charcot- Marie-Tooth Association (“CMTA”) requires facilitating the translation of new discoveries and breakthroughs to speed up the pace of CMT research and find effective therapies for the most common types of CMT. In order to implement its goals, the CMTA has formulated a strategy for the acceleration of research known as STAR. The CMTA recognizes that the development of research and effective therapies requires collaboration with the public and private, for-profit sectors. The CMTA encourages collaborative relationships with public and private sectors; however, such involvement requires a relationship of trust and at times such relationships may lead to Conflicts of Interest or Commitments (“Conflicts”) that may need to be reduced, managed or eliminated.
2. Consistent with the research mission of the CMTA, the CMTA has formed a STAR Advisory Board governance comprising a **Scientific Advisory Board**, a **Therapy Expert Board** and a **Clinical Expert Board**. The **Scientific Advisory Board** will be responsible for providing scientific input regarding identified projects recommended for funding. The **Therapy Expert Board** will provide guidance to ensure that projects and alliances have translational value for the CMTA’s STAR mission of advancing therapy development ,and are adequately framed such as to meet that objective. The Clinical Experts Board will contribute expertise and guidance in clinical trial design, biomarkers and patient recruitment.
3. The purpose of this policy is to facilitate best practices for ensuring open communication between Advisory board members and the CMTA. A further aim is to ensure that objectivity in the research and development of effective therapies is maintained, in order to preserve The credibility of the CMTA and Advisory Board members will be preserved through a transparent procedure for maintaining confidentiality (“Confidential Information”), and identifying and managing potential conflicts encountered by members of the STAR Advisory Boards.

Definitions

Confidential Information: To encourage open communication among Advisory Board members and the CMTA, each Advisory Board member agrees that any information presented at a STAR Advisory Board meeting or any other conference or call or meeting among Advisory Board members whether in a formal talk, PowerPoint presentation, poster session or discussion including but not limited to STAR research project proposals, project evaluations, considerations and funding process is confidential information and is presented with the restriction that such information will not be disclosed or disseminated to third parties for public use. All such information described above shall be referred to herein as “Confidential Information.”

Conflict of Commitment: Exists when an outside activity of an Advisory Board member requires a commitment that could interfere with an Advisory Board member’s obligation to the CMTA.

Conflict of Interest: Occurs when an Advisory Board member in a position of trust has a competing professional or personal interest that could undermine or jeopardize the Advisory Board member’s ability to fulfill his or her duties impartially and objectively.

Disclosure: An Advisory Board member’s disclosure of Conflict of Commitment or Conflict of Interest.

Investigator: Any person, regardless of title or position, who is responsible for research design, conduct or reporting (e.g. principal investigator, project director, clinical research associates)

Scope

This policy applies to all STAR Advisory Board members, including Scientific Advisory Board, Therapy Expert Board, and Clinical Expert Board members.

Procedure

Disclosure

Upon appointment to an Advisory Board, Advisory Board members must disclose to the CEO of the CMTA all Conflict of Interests and Conflicts of Commitment that are reasonably related to the duties and obligations owed to the CMTA as a STAR Advisory Board member.

Disclosure Review and Conflict Determination

All decisions as to whether a Conflict of Interest or Conflict of Commitment will interfere with the Advisory Board member's duties and obligations to the CMTA and specifically to the STAR program will be exclusively vested in and subject to the sole discretion of the CEO of the CMTA.

Confidentiality

All Confidential Information will be treated by each Advisory Board member as confidential and such information can only be revealed or disclosed as approved by the CEO of the CMTA or as required by applicable law.

Non-Compliance and Disciplinary Actions

Advisory Board members subject to this policy are expected to comply fully and promptly with it.

Advisory Board members who deliberately or repeatedly fail to fully and truthfully disclose Conflicts of Commitment and Conflicts of Interest or disclose Confidential Information will be subject to termination as a STAR Advisory Board member. In addition, the CMTA will have the right to pursue any and all legal remedies at law or equity to protect the Confidential Information from disclosure or recover damages as a result of any violation of this policy.