

The KDM5C KARES Foundation, Inc.
Scientific Advisory Board Expectations and Management Policy
Last updated: October, 2022

Scientific/Medical Advisory Board Responsibilities & Policies

Purpose: The purpose of the Scientific Advisory Board is to offer expertise on scientific and clinical developments and to ensure that the KARES Foundation's policies, research, grants, marketing, communications and publications meet the highest standards of scientific rigor and accuracy. This body will have a minimum of 3 Medical and/or Scientific Advisors

The activities of the volunteer members of the KARES Scientific Advisory Board are to be exclusively scientific and educational, including, but not limited to:

- A. Upholding the values and pursuing the mission of the KARES Foundation when representing the KARES Foundation;
- B. Reviewing strategic plans, agendas and supporting materials prior to board meetings;
- C. Reviewing and revising as requested 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, 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 and contribution to the mission of KARES;
- G. Attending in-person or virtual meetings to discuss scientific updates and goals for the upcoming year; and
- H. Providing recommendations for grants, events, and research that are in the best interests of the KARES Foundation.

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

- A. A three-year term of office upon appointment by the KARES Foundation Board of Directors, after the annual meeting, or upon any vacancy during the current year, with possible reappointment following the end of the term for an additional term.
- B. Any individual Advisory Board member may be removed with cause by the affirmative vote of a majority of the Board.

- C. Vacancies on the Advisory Board shall be filled by the Board if it deems appropriate. The failure to fill a vacancy shall not invalidate the decisions of the Advisory Board, provided that a quorum was reached.
- D. Approval by the Board of Directors for any activities performed on behalf of the organization prior to public dissemination.
- E. 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.

Scientific/Medical Advisory Board Conflict of Interest Policy

Each individual shall disclose to the KARES Foundation any personal or financial interest which they may have in any matter pending before the KARES Foundation and shall refrain from participation in any discussion and decision on such matter. Any member of the KARES Foundation Scientific/Medical Advisory Board shall agree and adhere to the KARES Foundation Conflict of Interest policies that also govern the Board of Directors.

Scientific/Medical Advisory Board Member Agreement

AFFIRMATIONS:

I hereby affirm the following (*initial each line*):

_____ I have received a copy of the KARES Foundation Conflict of Interest policy.

_____ I have read and understand the policy.

_____ I agree to comply with the policy.

_____ I understand that the KARES Foundation is a charitable organization and that in order to maintain its federal tax exemption it must engage primarily in activities which accomplish one or more of its stated tax-exempt purposes.

DISCLOSURES:

- 1. Do you have any Material Financial Interest (current or potential), including any compensation arrangement, as defined in the KARES Conflict of Interest policy?

___ Yes ___ No

If yes, please describe this Material Financial Interest:

If yes, has the financial interest been disclosed, as provided in the KARES Conflict of Interest policy?

Yes No

2. In the past, have you ever had a Material Financial Interest, including a compensation arrangement, as defined in the Conflict of Interest policy?

Yes No

If yes, please describe this Material Financial Interest, including when (approximately) this Material Financial Interest occurred:

If yes, has the financial interest been disclosed, as provided in the KARES Conflict of Interest policy?

Yes No

3. Are you employed by or do you belong to an organization that takes public positions on policy issues affecting KARES, the rare disease community, or its interests?

If yes, please describe this Policy Interest:

If yes, has this Policy Interest been disclosed, as provided in the KARES Conflict of Interest policy?

Yes No

4. Please describe below any other relationships, positions, or circumstances that you believe could constitute possible forms of Conflict of Interest not otherwise addressed above. If the answer is none, please write the word "None" below.

I hereby certify that the information set forth above is true and complete to the best of my knowledge. I have reviewed, and agree to abide by, the KARES Foundation Policy on Conflicts of Interest in effect as of the date of signature of this document. By signing my name below, I certify that I have read, understand, and agree to the information and expectations outlined in the Scientific/Medical Advisory Board Policies and Procedures for the KARES Foundation. I understand that a violation of the Scientific/Medical Advisory Board Policies and Procedures may result in consequent disciplinary action, including termination of my appointment on the Scientific/Medical Advisory Board for the KARES Foundation.

Name (Please Print)

Signature

Date (mm/dd/yyyy)