



Approved by the Board of Directors on February 21, 2021

Corporate Relations Policy

The FamilieSCN2A Foundation will enter into corporate relationships for the sole purpose of providing mission related benefits to its members and the SCN2A community. We will not accept any corporate donation or enter into any corporate relationship that would create a conflict of interest, or even its appearance, with the Foundation's mission, sound science, or board-approved policies. All procedures and formal agreements with corporate donors will be designed to prevent any undue influence upon The FamilieSCN2A Foundation. We will perform appropriate and adequate due diligence, with respect to all corporate donors, to ensure that the company's activities, affiliations and business practices do not compromise our mission.

In all relations with external organizations, The FamilieSCN2A Foundation will act in ways that will only enhance our credibility and professional recognition. In order to ensure that all corporate donations are in alignment with The FamilieSCN2A Foundation's mission and are always for the sole benefit of the SCN2A community, our Board of Directors has approved the following guidelines and principles regarding corporate support.

Types of Corporate Support

Financial and/or in-kind support in the form of grants and/or sponsorships for educational and communication vehicles (i.e., conferences, videos, podcasts, publications and community initiatives).

- Financial and/or in-kind support in the form of grants and/or sponsorships for fundraising purposes.
- Strategic alliances that provide improved services for constituents.
- Cause-related marketing.
- Health message promotion.
- Financial grants and/or professional support for clinical trials and research.



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Vested Corporate Interactions to Avoid

A vested corporation is one that either makes or offers products/services used by an individual with SCN2A-related diseases.

- The FamilieSCN2A Foundation will not endorse any other corporation's product, service or program.
- The FamilieSCN2A Foundation will not lend its name to license products, services or programs of other organizations.
- The FamilieSCN2A Foundation will not recognize or certify the quality or standards of a particular company, including its products and services.
- The FamilieSCN2A Foundation name and logo should not be associated with a specific branded product of an external company. References to the FamilieSCN2A website, phone number and address for the purposes of referral information are an exception to the above.

General Principles

The FamilieSCN2A Foundation will not endorse any corporation or product nor will it allow a corporation's interest to factor into its decision-making process. All unrestricted educational grants received by FamilieSCN2A will acknowledge and recognize the contributing corporate donor, not the company's product (i.e. specific drug).

- In exchange for contributions, FamilieSCN2A will allow standard recognition to include, but not be limited to, items such as signage and acknowledgement in Foundation publications. Additional types of recognition will be considered on a case-by-case basis, based on the type of funding or opportunity presented.
- The FamilieSCN2A Foundation will not accept grants that may adversely affect its nonprofit status.
- Revenue generated through corporations will be used to advance the mission of The FamilieSCN2A Foundation in accordance with the strategic plan.
- The FamilieSCN2A Foundation will maintain complete control of the development and implementation of all content and materials related to educational conferences and materials conducted by the Foundation.
- Corporations providing sponsorships for advocacy and research conferences or symposia will not influence conference content or selection of speakers.
- The FamilieSCN2A Foundation will maintain control and discretion over all corporate funds received and will ensure compliance with related grant agreements.



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The FamilieSCN2A Foundation Policy on Organizational Participation in Food and Drug Administration Hearings and Meetings

The following information details The FamilieSCN2A Foundation's official policy on organizational participation in Food and Drug Administration (FDA) hearings and meetings regarding the regulatory approval of drugs, biological products, and medical devices in accordance with its Corporate Relations Policy:

- The FamilieSCN2A Foundation will not generally provide testimony or submissions in its name in direct support for or against any drug, biological product, or medical device approval application. However, the Foundation may on occasion provide testimony, submissions, or participate in open or closed FDA meetings in its name to provide information about, or relevant to, SCN2A-related diseases, including information (e.g. evidence of community need, what constitutes evidence of clinical benefit, endpoints, etc.), which may be relevant to regulatory decisions regarding an application under FDA review or a product under development.
- Any request for The FamilieSCN2A Foundation to provide testimony, statements, or opinions either supporting or opposing specific drugs, biological products, or devices in FDA or regulatory approval proceedings shall be reviewed by the Scientific and Medical Advisory Board and our Board of Directors. These committees shall make a recommendation regarding whether The FamilieSCN2A Foundation should testify or take similar action. In the event that it is recommended that The FamilieSCN2A Foundation should provide testimony, statements, or opinions either supporting or opposing specific drugs, biological products, or devices in FDA or regulatory approval proceedings, final determination of the course of action to be taken by The FamilieSCN2A Foundation in an official capacity shall be made by the Board of Directors. If a representative of The FamilieSCN2A Foundation testifies before the FDA, that person will clearly disclose any conflict of interest prior to testimony or submission as is required at all FDA meetings and hearings. Nothing in this section prohibits the Executive Director or Research Coordinator from representing the interests of the FamilieSCN2A Foundation community in a manner that is non-specific to individual drugs, biological products, or medical devices.
- The FamilieSCN2A Foundation staff will monitor the development of drugs, biological products and devices relevant to SCN2A-related disorders, including the pendency of applications for FDA or other regulatory approval of such treatments, and provide this information to its members and the general public.
- In the dissemination of information concerning the development of treatments, officers and staff of The FamilieSCN2A Foundation will comply with the Corporate Relations Policy and refrain from taking any action that can be seen as endorsing any corporation's product, service, or program, except as provided above.



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- The Executive Director, together with the Board of Directors, will maintain complete control of the development and use of all content and materials produced or used by The FamilieSCN2A Foundation related to the dissemination of information concerning the development and regulatory approval of drugs, biological products, medical devices, or programs for the treatment of individuals with SCN2A-related disorders.
- Nothing in this policy impedes or discourages individual members of The FamilieSCN2A Foundation or its Scientific and Medical Advisory Board from participating in or testifying before the FDA or other regulatory panels, provided they make clear that they are not acting as a representative of The FamilieSCN2A Foundation.

The FamilieSCN2A Foundation Policy on timely requests

The FamilieSCN2A Foundation's staff and Board of Directors value transparent and timely communication. The Executive Director, the Foundation's sole employee, is the point of contact for Corporation engagement. We are happy to share information through our channels if given the opportunity to collaborate on the creation, review and edit.

- We are committed to responding to non urgent emails and phone calls within 48 hours
- Requests requiring Board of Directors approval will be reviewed on a bi-monthly basis
- Any requests requiring our Medical and Scientific Advisory Board review will be on a quarterly basis