



Approved by the Board of Directors on May 19, 2020

Corporate Relations Policy

The Dravet Syndrome Foundation (DSF) will enter into corporate relationships for the sole purpose of providing mission related benefits to its members and the Dravet community. DSF will not accept any corporate donation or enter into any corporate relationship that would create a conflict of interest, or even its appearance, with DSF'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 DSF.

DSF 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 DSF's mission.

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

Types of Corporate Support

Financial and/or in-kind support in the form of grants and/or sponsorships for educational and communications 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

Vested Corporate Interactions to Avoid

A vested corporation is one that either makes or offers products/services used by an individual with Dravet syndrome.

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

General Principles

DSF 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 DSF will acknowledge and recognize the contributing corporate donor, not the company's product (i.e. specific drug).

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

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DSF Policy on Organizational Participation in Food and Drug Administration Hearings and Meetings

The following information details DSF'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:

- DSF 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, DSF may on occasion provide testimony, submissions, or participate in open or closed FDA meetings in its name to provide information about, or relevant to, Dravet syndrome or 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 DSF 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 Science and Medical Advisory Boards and the DSF Board of Directors. These committees shall make a recommendation regarding whether DSF should testify or take similar action. In the event that it is recommended that DSF 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 DSF in an official capacity shall be made by the Board of Directors. If a representative of DSF 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 DSF community in a manner that is non-specific to individual drugs, biological products, or medical devices.



- DSF staff will monitor the development of drugs, biological products and devices relevant to Dravet syndrome, 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 DSF 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.
- 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 DSF 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 Dravet syndrome.
- Nothing in this policy impedes or discourages individual members of DSF, or its Medical and Scientific Advisory Boards 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 DSF.