



December 4, 2018

FamilieSCN2A Foundation: Requirements for Industry Interaction

The FamilieSCN2A Foundation works to create, and seeks to enhance a landscape that encourages investment in research by all stakeholders. This includes actively engaging and collaborating with pharmaceutical and biotech companies. The following requirements will help to ensure the highest level of ethical conduct is followed in the organization's collaborations with these for-profit companies. The goal in engaging companies is to enable the development of therapies to meet patient needs while maintaining independence and neutrality as a patient organization.

Company Engagement:

1. Board Members and members of the Scientific Advisory Committee will disclose any and all relationships with companies with whom the organization engages and will annually sign a statement agreeing to the organization's Conflict of Interest Policy.
2. The organization will collaborate with companies, at its discretion and in consultation with its scientific advisors, which are conducting ethical, high-quality research in a responsible manner, according to industry and international regulatory standards.
3. The organization will actively seek the guidance and utilize the expertise of its Scientific Advisory Board throughout the process of working with each company.

Data Collection:

The FamilieSCN2A Foundation strongly advocates that all data about a family's medical history, genetic mutation, and all bio-specimens collected (DNA, cell lines, etc) should be in 'pre-competitive' space and should be freely available to any qualified researcher.

This practice helps to amass a large number of families with relevant medical information, which is critical to make progress on any rare disease. It is a strategy used by many other groups and is strongly endorsed by Simons VIP Connect (and made possible by their data platform). This ensures that any researcher with a good idea will be able to design experiments and potentially develop treatments. We are committed for the long term to make all de-identified data and samples available to the research community to make it easier for more scientists to work to find treatments for families. We strongly believe this arrangement is in the best interest of families and the entire SCN2A Community.

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EIN # 47-3169795



Patient Engagement:

To avoid any potential appearance of conflict of interest, Board Members, who have a fiduciary responsibility to the organization and direct the acceptance and use of funds provided by pharmaceutical companies, should not testify at regulatory hearings. Patients and members of the community with a connection to the pharmaceutical company, such as relatives of an employee or owners of stock in the company, should also not testify at hearings.

Financial Contributions:

The organization can accept donations from pharmaceutical companies; however, Board Members and staff may not receive honoraria to speak on behalf of the organization. Travel expenses incurred to participate in disease-awareness activities may be reimbursed directly to the individual or the organization.

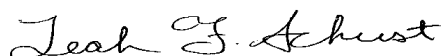
Clinical Trial and Approved Therapy Communication:

1. The organization will disseminate accurate, fair and balanced information about clinical trials provided by a pharmaceutical or **biotech** company without additional commentary or opinion that may influence an individual's decision to participate in a clinical trial or that may change the meaning of the information.
2. The organization does not communicate information in a manner that could be interpreted as advertising or promoting a drug or treatment that has not been approved.

The FamilieSCN2A Foundation recognizes the need for open lines of communication, connecting scientists, and forming partnerships with doctors, researchers, and patient organizations which help avoid duplication of efforts. We partner with organizations who share our priorities of finding effective treatments and a cure, and who share our integrity and values that support our mission. Global collaboration will get us closer to a cure of SCN2A related disorders.

Advocacy organizations, medical partners, industry or other parties interested in partnering with The FamilieSCN2A Foundation can contact Leah Schust, President and Founder, for more information.

Sincerely,



Leah Schust

President, Founder, Research Committee Chair