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# 2022 Industry Policy

Narcolepsy Network is the only US member-governed patient organization that represents the concerns and needs of people with narcolepsy and their supporters. An important part of our mission is to recognize, build and maintain relationships with the biopharmaceutical companies that have US Food and Drug Administration (FDA) approved medications or are developing potential treatments for individuals with narcolepsy. Our role is to provide accurate and unbiased educational information to people with narcolepsy and their families about available and future investigational clinical treatments and to advocate for the needs of our community around these therapies. Narcolepsy Network's hope is to realize a future where current and future therapies will continue to make a positive impact on the lives of the many children and adults affected by narcolepsy.

Narcolepsy Network upholds the following core values when working with industry partners:

1. Transparency and balance in providing industry information to people with narcolepsy and their supporters
2. Development of partnerships on topics of mutual interest
3. Respect for independence as the US membership-governed patient advocacy group
4. Reflection of the collective interests of family/people with narcolepsy
5. Ethical practices that ensure a professional boundary between people with narcolepsy, their supporters, and industry partners
6. Adherence to privacy regulations around patient and family information sharing
7. Open and timely communication with industry responding to Narcolepsy Network inquiries within 3 -5 business days

## Role of Industry Partners

The role of an industry sponsor is to inform Narcolepsy Network about its activities and programs related to narcolepsy and, where applicable, the benefits and risks of approved treatment and/or participating in an investigational clinical trial or study. In addition, companies are expected to share with Narcolepsy Network scientific and educational information for people with narcolepsy/supporters, and where applicable seek input from Narcolepsy Network into their efforts as they pertain to the needs of the community.

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Companies *may* benefit in working with Narcolepsy Network in a variety of ways, including:

1. Developing a unique perspective about narcolepsy and the patient experience and journey
2. Gaining exposure to the patient population where appropriate, while respecting patient privacy
3. Understanding the collective and individual priorities of the narcolepsy community
4. Acquiring knowledge of the disease and patients' preferences to inform clinical trial design *via a Narcolepsy Network managed process that may include patient surveys or organized listening sessions*
5. Advancing patient education on therapies and clinical development
6. Obtaining advocacy support during the regulatory review process

This interaction also provides opportunities for project collaboration including, but not limited to, general and medical education about the disease and advocacy for a product/treatment approval and health insurance reimbursement. Narcolepsy Network is actively building a relationship with the FDA in order to represent the voice of narcolepsy patients and provide family insights, as those priorities pertain to representing the need for approved clinical treatments. The primary liaison to companies for Narcolepsy Network is its Executive Director; Board members may also be appointed as secondary liaisons. All communication should be directed to the appointed primary liaison, to ensure proper coordination with the community. Narcolepsy Network will notify the company of any changes to the liaisons.

## Information Sharing with the Community

The aim of Narcolepsy Network in sharing information is to be a conduit of up-to-date, unbiased, accurate and balanced information for patients and families. This includes the latest information on research and clinical trials. It is critical that the information we provide to our members is made available in an organized, easily-accessible manner that is open and transparent.

## Examples of Narcolepsy Network Industry Partnerships

### Funding Opportunities

Narcolepsy Network will submit requests for targeted or unrestricted operating financial grants to assist in the management of the organization. The grants must be given without

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conditions, and *no quid pro quo* arrangement will be accepted. Monies that are received will benefit the work of Narcolepsy Network, its members, and the larger community, not just the subset served by the clinical research or product of the company.

### Sponsorships

Narcolepsy Network offers sponsorship opportunities to support an event, activity, or program relevant to a company's therapeutic areas or business interests. These sponsorships include a tangible set of benefits and recognition for the company.

### Ongoing Clinical Trial Information Sharing\*

Narcolepsy Network does not engage in fee-for-service agreements for clinical trial recruitment with biopharmaceutical companies or private vendors. Rather, Narcolepsy Network invites industry-sponsoring partners to participate in information sharing with our community, and may request a yearly unrestricted sponsorship grant to support our work in serving our community. We also share information on academic clinical studies.

Narcolepsy Network values clinical study and trial work that supports people with narcolepsy. In order to keep the public aware of opportunities, we share information on current studies and trials in a consistent and unbiased manner. We review all content, and approve all language, before we share such information with our members. Information for each active study or clinical trial will be shared on a regular basis via outreach channels such as: social media, e-newsletters, and targeted emails. Narcolepsy Network will also provide a listing on our website that links to either the National Institutes of Health (NIH) or a company's trial/study website.

*\*Please note Narcolepsy Network does not endorse, advise, recruit, or promote participation in any specific clinical trial or study.*

### Patient Engagement

Narcolepsy Network welcomes working with companies that want to engage with the community and are willing to do so in a structured manner. We can work with companies in a variety of ways to establish patient engagement opportunities. Our first step is to meet with the company to understand its goals for the project.

For example, we can engage patient survey work in an unconflicted manner. We require an industry-supported third party market research company to manage the survey in conjunction with the industry sponsor. Narcolepsy Network must review and have input into the patient survey design and content. We will work with either branded or unbranded

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studies. Narcolepsy Network also may request a high-level public report from these surveys that we are able to make available to our community. The schedule for delivering these patient surveys to the community will be determined in partnership with Narcolepsy Network and the industry sponsor.

Another example of patient engagement work includes organized sponsorship opportunities for patient presentations and/or patient advisory meetings, in order to directly hear about the patient experience and journey from our community members. Industry members may receive feedback on a variety of topics such as patient experience and journey, therapeutic needs and outcome measurements from a diverse audience that is screened by Narcolepsy Network. This work may be done with counsel from our Medical Advisory Board. *Because Narcolepsy Network is an unbiased, membership-governed organization, these presentations and meetings must be strictly educational—not marketing opportunities for the company and/or Narcolepsy Network.*

### Educational Projects

Narcolepsy Network also accepts corporate funds for collaborative educational projects. These efforts are generally unbranded projects between, or among, the companies and Narcolepsy Network. Narcolepsy Network is responsible for payment of services associated with these projects. Please note that Narcolepsy Network does not share material in any form that is directly intended to market a product. Narcolepsy Network also does not collaborate in industry projects or visibility efforts that relate directly to a company's product or clinical trial marketing goals.

### Consultants

Narcolepsy Network staff and Board cannot serve as paid consultants and/or working members on industry-sponsored patient advisory groups, or related industry-sponsored advocacy committees. We maintain this policy to ensure that the patient community, and the collective patient voice we represent, remain unconflicted with the many commercial interests in the narcolepsy space and because we often receive funding from our partners. However we will work with a company to determine alternate ways to engage in providing unconflicted patient advisory representation.