

# GOVERNANCE RECOMMENDATIONS FOR MEMBER ORGANIZATIONS

*New Recommendations for Ethical, Legal and Fair Governance of Board, Staff and Finances*

## ARTICLE 1 – PURPOSE

NORD, a 501(c)(3) organization, is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 300 patient organization members, is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

NORD was founded by patients and caregivers, galvanized by advocating for the Orphan Drug Act of 1983, which created financial incentives for the development of treatments for rare diseases. Since then and for the last 35 years, NORD has served as the hub of the rare disease community, leading efforts to connect patients, patient organizations with other stakeholders and driving progress for all.

NORD is the voice of the 30 million Americans with rare diseases and, as such, are always be guided by its determination of what is in the best interests of the patient community. NORD maintains independence in its advocacy positions and initiatives, which are formulated by senior staff, the board of directors, and NORD's medical advisors. NORD maintains independence in the editorial content of its educational materials.

NORD has developed these recommendations as a direct response to our member organizations seeking assistance in guidelines for healthy governance practices.

While time-consuming and a complex process, we know that when nonprofit leaders review and update their bylaws and existing governance policies, they are securing longer and healthier futures for their organizations.

NORD's recommended standards were produced after a thorough review of existing guidelines by various stakeholders in health, nonprofit and rare disease fields; these guidelines include the Alport Foundation, a NORD member organization, Policy for Engaging with Industry; the Better Business Bureau Wise Giving Alliance Accreditation Standards; Board Source; National Health Council Standards of Excellence Certification Program® for Voluntary Health Agencies Implementation Guide; Independent Sector's Principles for Good Governance and Ethical Practice, and the Pharmaceutical Research and Manufacturers of America PhRMA Principles on Interactions with Patient Organizations.

## KEY TO REFERENCES FOR INDUSTRY GUIDELINES:

**ASF:** Alport Syndrome Foundation

**BBB:** Better Business Bureau

**BS:** BoardSource

**IS:** Independent Sector

**NHC:** National Health Council

**AFP:** Association for Fundraising Professionals

**PhARMA:** Pharmaceutical Research and Manufacturers of America

## **ARTICLE II – ETHICAL GUIDELINES FOR INDUSTRY INTERACTION**

NORD engages with industry to advance the development of therapies and improve patient’s lives and care, while maintaining independence and neutrality as an independent organization. NORD member organizations are encouraged to create, and foster research by all stakeholders – this includes actively engaging and collaborating with pharmaceutical companies. The following suggestions are abbreviated from a larger set of guidelines from the Alport Syndrome Foundation, a NORD member organization. Some of the suggestions below may not pertain to all member organizations, but we expect that they can help with many organizations to ensure the highest level of ethical conduct is followed in the organization’s collaborations with pharmaceutical companies.

NORD encourages member organizations engaged in corporate relationships to have a board-approved policy that:

1. Enumerates the criteria for evaluating corporate relationships including mission-related benefit, independence and control, consistency with mission, income balance, and privacy;
2. Requires a written agreement with the corporation prior to entering the relationship;
3. Mandates the disclosure of the name of the individual corporation identified on Schedule of its Form 990 (more than the greater of \$5,000 or 2% of the total amount of contributions reported on line 1H of Part VIII of Form 990) and the aggregate amount of support provided by each corporation OR the total amount of corporate support from pharmaceutical, biotechnology, and medical device companies as a percentage of total organizational revenue;
4. Requires compliance with its corporate relations policy by divisions, chapters, and affiliates of the organization; and
5. Mandates the development of written operating procedures for the review and approval of corporate relationships and ongoing evaluation of such relationships. (NHC)

### **COMPANY ENGAGEMENT:**

1. Board members and members of the Medical 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 Medical and 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 Medical Advisory Committee throughout the process of working with each company.

### **FINANCIAL CONTRIBUTIONS:**

1. 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 disseminates accurate, fair and balanced information about clinical trials provided by the pharmaceutical 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.

## **NORD CORPORATE COUNCIL**

As an example of how industry members can interact with an organization in a positive, meaningful way, review how members of the NORD Corporate Council accept and adhere to the following Code of Conduct:

1. The purpose of the Corporate Council is to discuss issues of common interest related to orphan product development with the ultimate goal of developing safe, effective diagnostics and treatments for patients.
2. Corporate Council members understand and respect that NORD is the voice of the 30 million Americans with rare diseases and, as such, are always be guided by its determination of what is in the best interests of the patient community.
3. Corporate Council members understand and respect NORD's need to remain neutral with respect to specific products or services. NORD maintains independence in its advocacy positions and initiatives, which are formulated by senior staff, the board of directors, and NORD's medical advisors.
4. NORD maintains independence in the editorial content of its educational materials.
5. Corporate Council members seek to work in an active partnership among patients, health professionals, and industry.

## **ARTICLE III – RECOMMENDATIONS FOR GOOD GOVERNANCE**

Governance is all of the processes of governing, whether undertaken by a government, formal or informal organization or territory and whether through the laws, norms, power or language of an organized society. It relates to “the processes of interaction and decision-making among the actors involved in a collective problem that lead to the creation, reinforcement, or reproduction of social norms and institutions.” In lay terms, it could be described as the political processes that exist in between formal institutions. In business and outsourcing relationships, governance frameworks are built into relational contracts that foster long-term collaboration and innovation. Poor governance can lead to contract failure.

Rare disease nonprofits may be reluctant to develop advanced governance policies because of limited staff resources, time, effort and expertise. However, the lack of comprehensive policies can end up costing your rare disease organization much more work in the long run – in reputation and resources. The following guidelines are a suggestion for good governance policies.

## EFFECTIVE GOVERNANCE

1. The board should review organizational and governing instruments no less frequently than every five years. (IS)
2. The board must play a substantive role with management in developing, approving, and supporting organizational strategy. One of the board's primary responsibilities is to set the direction for the organization. Strategic planning serves as the road map for this direction and as the tool to assess progress. The full board needs to actively participate in and own the results of strategic planning. (BS)
3. The board should establish and review regularly the organization's mission and goals and should evaluate, no less frequently than every five years, the organization's programs, goals, and activities to be sure they advance its mission and make prudent use of its resources. (IS)
4. The board should review the bylaws periodically and ensure timely amendments when necessary. Bylaws formalize the board's structure and practices. The board's needs evolve over time, as do the external circumstances within which the organization and the board function. It is necessary to review the clauses periodically to verify their continued appropriateness and to assess what might be missing. An attorney should verify that the bylaws are in compliance with the state statutes. (BS)
5. The board of a charitable organization should include members with the diverse background (including, but not limited to, ethnicity, race, and gender perspectives), experience, and organizational and financial skills necessary to advance the organization's mission. (IS)
  - a. The board should be intentional in its recruitment and engagement of diverse board members and foster a culture of inclusivity. To value diversity is to respect and appreciate race; religion; skin color; gender and gender identity; ethnicity; nationality; sexual orientation; physical, mental, and developmental abilities; age; and socioeconomic status. Boards should commit to diversity and inclusion by establishing written policies and practices, subject to regular evaluation, that address strategic and intentional recruitment and engagement of diverse board members and ongoing commitment to inclusivity, including equal access to board leadership opportunities. (BS)
6. The board must be strategic about member recruitment and define an ideal composition for itself based on the organization's priorities at any given moment. A matrix for board composition facilitates the board's strategic recruitment efforts. By analyzing the present composition of the board, the governance committee — or the full board if no committee is needed — is able to best determine what qualities, characteristics, and perspectives are already present on the board. When analyzed in light of the organizational strategies, a matrix helps the board identify where gaps exist and then direct recruitment efforts to fill those gaps. (BS)
7. The board should adopt term limits. Regular turnover among board members encourages the board to pay attention to its composition, helps to avoid stagnation, offers the opportunity to expand the board's circle of contacts and influence, and provides a respectful and efficient method for removing unproductive members. Seventy-one percent of nonprofit boards have term limits for board members, and the most common are two consecutive three-year terms. Term limits do not prevent valuable members from remaining in the service of the organization or the board in another capacity. An exception is the family foundation that may have a limited pool of qualified and interested candidates. (BS)
8. The board should have a written job description outlining the responsibilities of the full board and of individual board members. Board service comes with expectations and obligations. A written

job description defines the collective governance role of the board and reminds it of the various activities that need to be incorporated in the board's annual calendar. The board also should draft a separate set of expectations for individual board members to help them meet their obligations of transparency, integrity, and patient-centeredness and engage productively in the board's work. (BS)

9. The board treasurer cannot also hold the position of board chair or executive director. (IS)

## **LEGAL COMPLIANCE AND PUBLIC DISCLOSURE**

1. A charitable organization must comply with all applicable federal laws and regulations, as well as applicable laws and regulations of the states and the local jurisdictions in which it is formed or operates. If the organization conducts programs outside the United States, it must also abide by applicable international laws, regulations, and conventions. (IS)
2. The full board should review the Form 990 before it is filed. Form 990 is the most widely viewed public document concerning the organization, its finances, activities, and governance practices. It is important that board members are familiar with its contents and that it accurately presents the organization to its constituents, donors, and media. (BS)
3. The nonprofit should post its Form 990 on its own website. Form 990 is a public document and one of the primary tools to shed light on the organization and its finances, activities, and governance practices. By posting the Form 990 on the organization's own website and making it easily accessible, the board is supporting and promoting methodical transparency. (BS)
4. The board must ensure that no records are destroyed when the organization is under federal investigation. Federal law states what must happen in the event the organization is under official investigation. All organizations should have a policy for document destruction and retention to ensure that the law is understood and respected. (BS)

## **FINANCIAL OVERSIGHT**

1. The board of a charitable organization must institute policies and procedures to ensure that the organization (and, if applicable, its subsidiaries) manages its funding responsibly, e.g., clear written policies for reimbursing expenses for travel. (IS)
2. The organization demonstrates a broad base of public support in its funding sources by: 1) maintaining its section 501(c)(3) public charity status in accordance with the requirements of the Internal Revenue Code and Treasury regulations and 2) developing a Board-approved gift acceptance policy that must cover: a) a requirement for mission-related benefit, independence and control, consistency, and balance; b) types of acceptable donations (i.e., property, stock); c) types of acceptable donors (i.e., individual, foundation); d) criteria for refusal; and e) process and operating procedures for evaluating gifts. (NHC)
3. The organization should avoid accumulating funds that could be used for current program activities. To meet this standard, the charity's unrestricted net assets available for use should not be more than three times the size of the past year's expenses or three times the size of the current year's budget, whichever is higher. (BBB)

## **FUNDRAISING**

1. Fundraising, publicity, and promotional activities are: a) truthful and not deceptive; b) void of techniques intended to deceive, coerce, harass, or intimidate potential contributors; and c) contain the name of the organization, its purpose, and the address from which additional information may be obtained. (NHC)

2. The organization includes on any website(s) that solicit contributions the following information: the mailing address of the organization; electronic access to its most recent IRS Form 990; conflict of interest policy; and whistleblower policy. (NHC)
3. The organization obtains prior permission before using the names of individuals, organizations, or companies in ways which imply endorsement of program or fundraising activities. (NHC)
4. A charitable organization should adopt clear policies in advance to determine whether accepting certain gifts would compromise its ethics, financial circumstances, program focus, or other interests. (IS)
5. Contributions must be used for purposes consistent with the donor's intent, whether as described in the relevant solicitation materials or as specifically directed by the donor. (IS)
6. A charitable organization must provide donors with specific acknowledgments of charitable contributions, in accordance with IRS requirements, as well as information to facilitate the donors' compliance with tax law requirements. (IS)
7. Have solicitations and informational materials, distributed by any means, that are accurate, truthful and not misleading, both in whole and in part. Appeals that omit a clear description of program(s) for which contributions are sought will not meet this standard. A charity should also be able to substantiate that the timing and nature of its expenditures are in accordance with what is stated, expressed, or implied in the charity's solicitations. (BBB)
8. Clearly disclose how the charity benefits from the sale of products or services (i.e., cause-related marketing) that state or imply that a charity will benefit from a consumer sale or transaction. Such promotions should disclose, at the point of solicitation: a) the actual or anticipated portion of the purchase price that will benefit the charity (e.g., 5 cents will be contributed to abc charity for every xyz company product sold), b) the duration of the campaign (e.g., the month of October), and c) any maximum or guaranteed minimum contribution amount (e.g., up to a maximum of \$200,000). (BBB)
9. A charitable organization should provide appropriate training and supervision of the people soliciting funds on its behalf to ensure that they understand their responsibilities and applicable federal, state, and local laws, and do not employ techniques that are coercive, intimidating, or intended to harass potential donors. (IS)
10. A charitable organization should not compensate internal or external fundraisers based on a commission or a percentage of the amount raised. (IS)

## **WHISTLEBLOWER POLICY**

1. The board must ensure that no employee or volunteer is punished or discriminated against because he or she reported improper conduct. Federal law states what must happen if alleged improper conduct is reported. All organizations should have a formal, written process to deal with complaints and prevent retaliation. If under investigation, the organization is responsible for showing that it follows a systemized process to address whistleblower cases. (BS) and/or: a charitable organization should establish and implement policies and procedures that enable individuals to come forward with information on illegal practices or violations of organizational policies. This whistleblower policy should specify that the organization will not retaliate against, and will seek to protect the confidentiality of, individuals who make good-faith reports. (IS)

## ORGANIZATIONS WITH STAFF

1. Organizations with three or more paid staff have a written statement of personnel policies, reviewed periodically (at least every three years) by legal counsel to ensure compliance with applicable state and federal law and reviewed annually by the chief staff executive or other authorized senior staff person to assure appropriate personnel practices. (NHC)
2. The organization employs a chief staff executive either directly or through outsourced management. (NHC)
3. The board should hire, oversee, and annually evaluate the performance of the chief executive officer of the organization. It should conduct such an evaluation prior to any change in that officer's compensation, unless there is a multi-year contract in force or the change consists solely of routine adjustments for inflation or cost of living. (IS)
  - a. The board must develop a written job description for the chief executive and together with the chief executive define the annual expectations. The chief executive can remain accountable for his or her performance only if the position is well defined and annual goals and expectations are mutually agreed upon. (BS)
  - b. The board must formalize a process for setting appropriate compensation for the chief executive and approve the compensation package. The board needs to establish well-defined guidelines on how to determine appropriate compensation for the organization's chief executive. If the board offers too little, it could lose the chief executive to competing organizations; if it offers too much, it risks providing excess benefits and subjecting itself and the organization to intermediate sanctions. The board should follow the IRS's safe harbor measures and rely on comparative data, have the compensation decision determined by independent board members, and contemporaneously record the decision-making process. The full board should approve both the process and the resulting compensation package. (BS)
  - c. The board must evaluate the chief executive's performance annually; the evaluation should be written and involve the full board. A formal evaluation, based on well-defined and mutually agreed upon expectations, benefits and protects both the chief executive and the board. Even if the board chair or a committee leads the evaluation, the full board must participate by being given the opportunity to provide feedback, approve the final evaluation, and ensure all compensation recommendations are appropriate. The evaluation should include 360-degree feedback from the organizations leadership team so the board has an opportunity to gain additional insights from those working closely with the CEO on a daily basis. (BS)
4. The chief executive should be an ex officio, non-voting member of the board. The chief executive's input in board meeting deliberation is instrumental and invaluable for informed decision making. However, to avoid actual or perceived conflicts of interest, questions concerning accountability, or blurring the line between oversight and execution, chief executives should be non-voting members of the board, unless not permitted by law. (BS)