



NORD[®]
National Organization for Rare Disorders

2019 Standards of Excellence for NORD Member Organizations

New Requirements and Recommendations

The National Organization for Rare Disorders (NORD) was founded on the principles of collaboration and a united voice, and we provide guidance and support at all phases of development, as organizations evolve.

NORD's organizational membership community provides a united force for advocacy, research and medical advancements, policy successes, public awareness and support for the 30 million Americans living with rare diseases. Our organizations represent a broad range of disease-specific communities and provide leadership to advance the goals we all share.

For the last 35 years since our inception, NORD has maintained the highest level of integrity and transparency in its governance; our reputation for leading with integrity – and with an unbiased patient voice – is known and respected on Capitol Hill and among stakeholders in the rare disease community.

Effective 2018, NORD has adopted a set of operating practices to ensure that its Member Organizations, 501(c)3 patient advocacy organizations maintain ethical standards and integrity from industry and other influences.

Please email NORD's Membership Team for assistance on meeting these qualifications. Our Team can provide templates for:

- Bylaws
- Conflict of Interest Policy for Board and Staff
- Operating Budget
- Medical Advisory Board Policies and Procedures
- Privacy Policy

For National and International Membership:

- A mission and programs that are compatible with NORD's goal of being patient-centered, and advocating on behalf of patients in the rare disease community.
- Proof of tax-exempt status pursuant to Section 501(c)(3) of the Internal Revenue Code, or the international equivalent of this status.
- Dated by-laws showing that your mission and programs are compatible with NORD's goal of being patient-centered, and advocating on behalf of patients in the rare disease community. **Bylaws must also detail the process for electing board members, as well as board term limits and a maximum number of consecutive terms a board member may serve.** ^{NEW}
- **Programs that engage patients, caregivers, medical professionals and supporters in one or more of the following ways: research, professional education, public education & health promotion, health services, community services, advocacy and social action.** ^{NEW}

- ***An up-to-date website that fully reflects your mission and your diverse patient voices.*** ^{NEW}
- A minimum of 5 Board Members that meet at least twice annually (in-person or by conference call).
- A minimum of 3 Medical and/or Scientific Advisors; **a policy and procedures document for expectations and management of this Medical Advisory Board. Organizations have 2 years from approval of their membership to meet this standard.** ^{NEW}
- **Any medical information your organization provides must be medically reviewed and vetted for accuracy by scientific or medical advisors.** ^{NEW}
- A Board-approved Annual Operating Budget.
- A Conflict-of-Interest Policy for Board and Staff. **NORD Member Organizations must implement a conflict-of-interest policy applicable to the board and key staff, reviewed and signed on an annual basis. Your conflict-of-interest policies must clarify what a conflict of interest is, what board members and employees must do to disclose possible conflicts of interest, and what board members and employees should do to avoid acting inappropriately if and when a conflict of interest does arise.**

The conflict-of-interest policy should clearly define a consistent process for dealing with conflicts including

- Defining responsible parties, financial interest**
- Determining whether a conflict of interest exists**
- Procedures for addressing the conflict of interest**
- Violations of the conflicts-of-interest policy**
- Disclosure and recusal, consequences for violations.**

Your Board of Directors must not directly or indirectly have a significant business relationship with your organization which might affect independence in decision making – including, but not limited to employment by a corporation or for-profit enterprise with a vested interest in your disease state, organization and policies. ^{NEW}

- A Privacy Policy that protects the identity of the patients and families with whom your organization works.
- **Your organization must disclose on your website how donations are used. This may involve posting the Form 990, an annual report, or other appropriate information on financials, income, expenses, programs and beneficiaries. By posting the Form 990 or other appropriate financial information online and making it easily accessible, your organization is supporting and promoting methodical transparency.** ^{NEW}

Categories of Organizational Membership

1. **National Members** are U.S. based-patient organizations with 501(c)(3) tax-exempt status
2. **National Associate Members** are U.S. based patient organizations that have currently filed with the Internal Revenue Service and are awaiting approval for their 501(c)3 tax exempt status. Associate Members will be members on the contingency of approval and have six months to submit documentation of approval of their tax status **NEW**
3. **International Members** are organizations operating outside of the U.S. that have globally recognized tax-exempt status
4. **International Partners** are rare disease umbrella organizations operating outside of the U.S. that have a strategic partnership with NORD

International Partnership is for umbrella organizations operating outside of the U.S. that NORD has a strategic partnership or Memorandum of Understanding with that outlines a shared commitment to improving the lives of rare disease patients and families through collaboration. *Organizations interested in International Partnership should contact: Debbie Drell, Director of Membership at ddrell@rarediseases.org.*