



NATIONAL SPASMODIC DYSPHONIA ASSOCIATION

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CODE OF ETHICS

I. INTRODUCTION

The Code of Ethics of the National Spasmodic Dysphonia Association (NSDA) is intended to reinforce the values and standards of conduct applicable to NSDA and to all individuals who act on behalf of NSDA. The purpose of the Code is to promote ethical conduct throughout the organization and to ensure compliance with the public trust which supports the mission of NSDA. The Code applies to all individuals who perform services on behalf of NSDA, including:

- NSDA Board of Directors
- NSDA Executive Director and all other employees of NSDA and consultants who provide services to NSDA
- NSDA Regional Coordinators
- NSDA Support Group Leaders
- NSDA Area Contact Persons
- NSDA Bulletin Board Moderators
- NSDA Honorary Board
- NSDA Medical Advisory Board

All such persons are expected to read and understand this Code, uphold these standards in day-to-day activities and comply with all applicable laws and regulations and with all policies and procedures adopted by NSDA.

II. NSDA'S MISSION

All actions taken on behalf of NSDA and all statements and policies issued by the organization should be consistent with and in furtherance of the mission of NSDA:

To advance medical research into the causes of and treatments for spasmodic dysphonia, promote physician and public awareness of the disorder, and sponsor support groups for patients and their families.

III. HONEST AND ETHICAL CONDUCT

All persons acting on behalf of NSDA are expected to meet the highest standards of professionalism, integrity, honesty and ethical conduct. This includes the responsibility to comply with applicable laws and regulations. If there is any question about the rules that apply to activities undertaken on behalf of NSDA, then outside advice should be sought.

IV. PATIENT RIGHTS

The individuals who seek advice, support or assistance from NSDA have come to us because of a specific medical condition. It is extremely important for NSDA and those who represent NSDA to be sensitive to the privacy rights of these individuals. Personal data about NSDA members and support group members, or about individuals who seek advice on the NSDA Bulletin Board, must be treated with care and must not be disclosed outside NSDA without specific consent of such persons.

V. MEDICAL INQUIRIES

When inquiries about a medical condition are received by NSDA or persons representing NSDA, it is their responsibility to give timely, accurate and constructive responses. Advice given by NSDA representatives should be limited to referring patients to information published by NSDA regarding treatment options for spasmodic dysphonia. This information is reviewed by NSDA's Medical Advisory Board and represents the Medical Advisory Board's best understanding of the current state of clinical findings and research. The criteria for inclusion of specific treatments are based on whether treatment protocols have been verified by publication of peer-reviewed research and whether they have been endorsed by general consensus of experts from the fields of neurology, otolaryngology and speech pathology. At the same time, individuals with spasmodic dysphonia who are in NSDA leadership positions, like all other SD patients who participate in NSDA activities, are encouraged to volunteer information about their own experiences with SD to help support and educate others. This should not be framed as medical advice and the leader's personal experiences should be clearly characterized as such and not as advice from NSDA. In particular, when speaking on behalf of NSDA, representatives should not endorse, praise or criticize specific health care professionals or express opinions in favor of or against specific treatment protocols.

VI. FINANCIAL RESPONSIBILITY

NSDA relies upon financial contributions and membership fees to support the organization. It is important for all members of the NSDA Staff and its Board of Directors to use such funds wisely and with restraint, with consideration for the future of the organization. Budget planning and financial oversight should be a high priority of the Board and the Staff, and periodic audit of financial processes and procedures should take place to ensure that financial controls are appropriate and to avoid improprieties in financial accounting.

VII. CONFLICTS OF INTEREST

Each person subject to this Code of Ethics should avoid all actual or apparent conflicts of interest. A conflict of interest exists where the interests of or benefits to an individual may conflict with the interests of or benefits to NSDA, such as any decision from which the individual could derive personal benefit. If an individual believes that he or she has such a conflict, he or she should immediately disclose it to the other members of the organization involved in the decision or action and should abstain from participating in the decision or action.

VIII. EMPLOYMENT STANDARDS

NSDA is committed to treating its employees and others who provide services to the organization with fairness and respect. NSDA strives to practice inclusiveness and to encourage diversity and equality of opportunity. NSDA should comply with all applicable laws and regulations in its hiring and management of employees and consultants.

IX. COMMUNITY RESPONSIBILITY

NSDA strives to be a cooperative and valued member of all the communities with which it interacts. This includes the medical and medical research communities, with whom NSDA cooperates to further research into causes of and treatments for spasmodic dysphonia. It also includes non-profit organizations that support other medical conditions that are related to spasmodic dysphonia. NSDA also strives to be a responsible member of the local communities where its individual members reside and its support groups operate.

X. FUNDRAISING

NSDA's fundraising practices should be consistent with its mission and with the organization's capacities and should always be respectful of donor interests. All fundraising should reflect a foundation of truthfulness and responsible stewardship. All fundraising should employ methods which promote the public's trust through the use of accurate and honest representations. The organization should at all times strive to honor the intentions of the donor.

XI. GOVERNANCE

In its Board of Directors, the NSDA has an active governing body responsible for setting the strategic direction of the organization and overseeing its finances, operations and policies. It seeks to engage Board members who have the requisite skills and experience to carry out their duties and who can devote sufficient time to the organization to properly oversee the activities of the Executive Director and Staff. The Board of Directors should ensure that the organization is conducting its affairs with integrity and transparency, that the Staff is responsibly and prudently managing the resources of the organization and that the provisions of this Code of Ethics are being complied with.

XII. COMPLIANCE WITH THE CODE

Complaints about an alleged breach of the NSDA Code of Ethics should be made in writing to the NSDA Ethics Committee. This committee consists of the President of the NSDA and two other directors not on the Executive Committee. Directors serving on the Ethics Committee shall be appointed at each Annual General Meeting of the NSDA Board of Directors.