



National Spasmodic Dysphonia Association (NSDA)

Spasmodic Dysphonia

Spasmodic dysphonia (SD) is a neurological voice disorder that involves “spasms” of the vocal cords causing interruptions of speech and affecting the voice quality. It can cause the voice to break on certain words, sound strained and shaking; or it can be breathy, fading away to a whisper.

Vision

The Vision of the National Spasmodic Dysphonia Association is to ensure the ongoing viability of the organization that will continue to lead the effort to eradicate spasmodic dysphonia.

Mission

The Mission of the National Spasmodic Dysphonia Association is to advance medical research into the causes of and treatments for spasmodic dysphonia, promote physician and public awareness of the disorder, and sponsor support activities for spasmodic dysphonia patients and their families.

Core Values

The Core Values of the National Spasmodic Dysphonia Association are the beliefs that govern our actions and decisions for the organization and reflect our commitment to the individuals with spasmodic dysphonia.

Integrity: *We act with honesty and transparency toward our commitments to the spasmodic dysphonia community and the public.*

Through our Board members, volunteers and staff, the NSDA adheres to the highest moral and ethical principles as we serve the spasmodic dysphonia community and interact with those who support the organization.

Responsibility: *We fulfill the purpose of the NSDA’s mission and vision with accountability.*

The NSDA is truthful in its solicitation and expenditure of funds, consistent with the needs of the spasmodic dysphonia community.

Respect: *We have regard for the worth and dignity of individuals.*

The NSDA values and respects all people, knowing that those searching for information or help and our donors both come from a diverse community.

Honesty: *We carry out our responsibilities with truthfulness in all aspects of the NSDA’s operations and activities.*

Communicating honestly advances our mission. We provide information about the NSDA clearly, coherently and with all the necessary detail to fulfill our mission.

Openness: *We inform the spasmodic dysphonia community and the public about our activities in a responsive and timely manner.*

Understanding spasmodic dysphonia is a work in progress. Working together, we will share new information and honestly admit what we don’t know about this disorder.

Fairness: *We treat the spasmodic dysphonia community, donors, volunteers and staff with equity.*

The NSDA treats all people with dignity and recognizes that each person matters in themselves. We strive to provide everyone with access to information and help.

Empathy: *We want people diagnosed with spasmodic dysphonia to know that we understand.*

It’s not unusual for a person with SD to think at some point that he/she is the only person with this strange vocal disorder. That is certainly not the case, and the NSDA wants you to know that we understand what you are going through as a person with spasmodic dysphonia, or a family member or friend of a person with spasmodic dysphonia, and we support you.



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 Representatives
- NSDA Support Group Leaders
- NSDA Area Contact Persons
- NSDA Bulletin Board Moderators
- NSDA Honorary Board
- NSDA Medical Advisory Board
- NSDA Scientific 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 activities for spasmodic dysphonia 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. The criteria for inclusion of specific treatments are based on whether treatment protocols have been verified by publication of peer-reviewed research and/or whether they have been endorsed by NSDA's Medical Advisory Board and Scientific Advisory Board after evaluating the current state of clinical findings and research.

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.

In addition, this includes the use of the NSDA mailing/e-mail list for personal use, social networks, or business gain. Information distributed or received by an individual through a person's role as a volunteer for the NSDA must be directly related to the work of the organization.

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.

XIII. WHISTLEBLOWER PROTECTION

The NSDA requires directors, officers, employees and volunteers to observe high standards of business and personal ethics on the conduct of their duties and responsibilities. As employees and representatives of the NSDA, we must practice honesty and integrity in fulfilling our responsibilities and comply with all applicable laws and regulations.

Reporting Responsibility: This Whistleblower policy is intended to encourage and enable employees and others to raise serious concerns internally so that the NSDA can address and correct inappropriate conduct and actions. It is the responsibility of all Board members, officers, employees and volunteers to report concerns about violations of the NSDA's Code of Ethics or suspected violations of law or regulations that govern the NSDA's operations.

No Retaliation: It is contrary to the values of the NSDA for anyone to retaliate against any Board member, officer, employee or volunteer who in good faith reports an ethics violation or a suspected violation of law, such as a complaint of discrimination, or suspected fraud, or suspected violation of any regulation governing the operations of the NSDA. An employee who retaliates against someone who has reported a violation in good faith is subject to discipline up to and including termination of employment.

Reporting Procedure: The NSDA has an open door policy and suggests that employees share their questions, concerns, suggestions or complaints with their supervisor. If you are not comfortable speaking with your supervisor or you are not satisfied with your supervisor's response, you are encouraged to speak with the President of the NSDA or a member of the Board of Directors Executive Committee. Supervisors and managers are required to report complaints or concerns about suspected ethical and legal violations in writing to the Chairman of the NSDA's Ethics Committee, who has the responsibility to investigate all reported complaints. Employees with concerns or complaints may also submit their concerns in writing directly to their supervisor or the Executive Director or the Chairman of the NSDA's Ethics Committee.

Chairman of the NSDA's Ethics Committee: The Chairman of the NSDA's Ethics Committee is responsible for ensuring that all complaints about unethical or illegal conduct are investigated and resolved. The Chairman of the NSDA Ethics Committee will advise the Executive Director and/or the Board of Directors of all complaints and their resolution and will report at least annually to the Treasurer on compliance activity relating to accounting or alleged financial improprieties.

Accounting and Auditing Matters: The Chairman of NSDA's Ethics Committee shall immediately notify the NSDA Audit Committee and Treasurer of any concerns or complaints regarding corporate accounting practices, internal controls or auditing and work with the Audit Committee and Treasurer until the matter is resolved.

Acting in Good Faith: Anyone filing a written complaint concerning a violation or suspected violation must be acting in good faith and have reasonable grounds for believing the information disclosed indicates a violation. Any allegations that prove not to be substantiated and which prove to have been made maliciously or knowingly to be false will be viewed as a serious disciplinary offense.

Confidentiality: Violations or suspected violations may be submitted on a confidential basis by the complainant. Reports of violations or suspected violations will be kept confidential to the extent possible, consistent with the need to conduct an adequate investigation.

Handling of Reported Violations: The Chairman of NSDA's Ethics Committee will notify the person who submitted a complaint and acknowledge receipt of the reported violation or suspected violation. All reports will be promptly investigated and appropriate corrective action will be taken if warranted by the investigation.