GUIDELINES FOR ETHICAL BEHAVIOR RELATING TO CLINICAL PRACTICE ISSUES IN NEUROMUSCULAR AND ELECTRODIAGNOSTIC MEDICINE

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The American Association of Neuromuscular and Electrodiagnostic Medicine (AANEM) developed the following guidelines to formalize the ethical standards that neuromuscular and electrodiagnostic (EDX) physicians should observe in their clinical and scientific activities. Neuromuscular and EDX medicine is a subspecialty of medicine that focuses on evaluation, diagnosis, and comprehensive medical management, including rehabilitation of individuals with neuromuscular disorders. Physicians working in this subspecialty focus on disorders of the motor unit, including muscle, neuromuscular junction, axon, plexus, nerve root and anterior horn cell, and the peripheral nerves (motor and sensory). The neuromuscular and EDX physician's goal is to diagnose and treat these conditions so as to mitigate their impact and improve the patient's quality of life. The guidelines were originally modeled after the Code of Professional Conduct of the American Academy of Neurology, and are consistent with the Principles of Medical Ethics as adopted by the American Medical Association, and represent a revision of previous guidelines of the AANEM. Violation of these guidelines may provide grounds for disciplinary action as outlined in Article 10.0 of the AANEM bylaws and the AANEM's Disciplinary Policies and Procedures.

Abbreviations: AANEM, American Association of Neuromuscular and Electrodiagnostic Medicine; EDX, electrodiagnostic medicine; EMG, electromyography; FDA, Food and Drug Administration; HIPAA, Health Insurance Portability and Accountability Act; HIV, human immunodeficiency virus; IRB, institutional review board; NCS, nerve conduction study

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1. THE PATIENT–PHYSICIAN RELATIONSHIP IN NEUROMUSCULAR AND ELECTRODIAGNOSTIC MEDICINE

1.1. The Patient–Physician Relationship. The relationship between the patient and the physician is a key component to assure patients are provided excellent care. The quality of this relationship can impact not only the success of the outcome of the interaction between patient and physician, but also the outcome of the patient's treatment. The physician has a fiduciary duty to safeguard the interests of the patient first. The physician must practice competently, respect patient autonomy and confidentiality, maintain patient safety, and protect the patient's best interests.

1.2. Beginning and Ending the Relationship. The physician is free to decide whether to perform an EDX or neuromuscular consultation on a particular patient. The physician should not decline the consultation on the basis of the patient's race, religious creed, national origin, gender, sexual orientation, or other personal characteristics. The physician also should not decline a consultation on the basis of the patient's known or suspected medical diagnosis. The physician should decline the performance of the EDX or neuromuscular consultation if he or she believes it to be unnecessary or not beneficial to the patient.

If possible, it is best for the physician and the referring physician to concur on who should inform the patient (or designated surrogate) of the results of the EDX or neuromuscular consultation. The physician should discuss the reason for the consultation and the methods to be employed with the patient. The physician should advise the patient as to who will be providing the patient with the results of the test. If the patient has a diagnosis that does not require EDX or neuromuscular testing, the physician should so inform the patient and cancel the study or give the patient the right to cancel the study (see Section 5.1).

Once the consultation has begun, the physician should complete the consultation process unless the patient ends the relationship before the consultation

can be completed, or if medical contraindications to completing the consultation become apparent during the consultation. After completion, the physician should return the patient to the care of the referring physician. If the patient does not have a referring physician, the physician should take responsibility for urgent care of the patient until appropriate referral can be made.

1.3. Informed Consent in Clinical Consultation. The physician must obtain valid consent from the patient or, when the patient is not competent to give such consent, from the patient's appropriate surrogate decision-maker. The physician must disclose information that the average person would need to know to make an appropriate medical decision. This information must include the benefits and risks of the proposed tests and should include costs of the proposed tests, if the patient desires this information. If the patient is referred for evaluation of a painful symptom, the physician should explain that the EDX studies are directed toward certain measurable peripheral nerve abnormalities, not whether pain is present or absent. Consent must be given voluntarily by the patient. If reasonable explanation fails to elicit a patient's consent to carry out the EDX consultation, the physician should not undertake the evaluation. The patient may negate a prior consent; if this occurs at any point during testing, the physician should not continue with the examination. Physicians must comply with applicable state and federal law governing informed consent requirements.

Federal Food and Drug Administration (FDA) and institutional review board (IRB) rules should be followed when conducting experimental or investigational studies of procedures, pharmaceuticals, or medical devices that involve human subjects (see Section 7).

On occasion, neuromuscular consultation or EDX testing must be performed on patients who cannot give consent. If a legal guardian is present, or if the patient has designated a surrogate decision-maker through a current and valid durable healthcare power of attorney, that person should be consulted. If the patient lacks decisional capacity, the guardian or surrogate decision-maker is unavailable, and the situation is an emergency, the physician may proceed without consent.

1.4. Patient Communication, Comfort, and Preparation. The physician has a duty to communicate with the patient. The physician should convey relevant information in terms the patient can understand and allow adequate opportunity for the patient to raise questions and discuss matters related to the neuromuscular and/or EDX evaluation. Physicians should make every effort to ensure that patients are adequately prepared for the planned neuromuscular evaluation and/or EDX procedures and that they are made as comfortable as possible during the examination. Physicians should be attentive to signs of patient discomfort and safety concerns, and resolve them before proceeding. Physicians may decide whether to admit family members or significant others into the examination room during testing to provide support. Informing the patient of the findings of the examination should be coordinated with the referring physician (see Section 1.2). Moreover, suggestions for changes in clinical management should generally be made to the referring physician rather than the patient unless the referring physician has requested that the physician participate in the direct clinical management of the patient.

1.5. Medical Risk to the Physician. The AANEM recognizes that physicians have needs and concerns that are relevant for ethical decision-making in the context of consultation. At the same time, a physician should provide appropriate, compassionate care to all patients, including patients with infectious and other communicable diseases (e.g., human immunodeficiency virus or antibiotic-resistant infections). A physician should not deny care to a patient solely because of real or perceived medical risk to the physician. Physicians must utilize appropriate universal precautions during the examination of any patient to minimize their own medical risk.

1.6. Ethical Considerations and the Management of Neuromuscular Disease. The specialist providing care to patients with neuromuscular disease is likely to encounter a number of situations during the care of his or her patients, which will raise ethical questions. Some neuromuscular disorders are progressive or debilitating and may impact a patient's autonomy or competence. Many of the neuromuscular disorders have limited treatments, which may lead patients to seek unproven interventions. Others may have effective but costly treatments that insurance may not cover or which patients may not be able to afford. Still others are known to shorten a patient's life expectancy with the prospect of a challenging final few months of life—leading a patient to seek alternatives for end-of-life care.

1.6.1. Discussion of Disease Implications. First and foremost, physicians must provide the best diagnostic and management skills to their patients of which they are capable. They also have a duty to discuss openly with their patients the implications of their patients' diagnoses. This discussion may require a great deal of sensitivity and compassion on the physician's part, particularly if the diagnosis is one that will severely impact the patient's quality

or length of life. The physician's counsel should be honest yet allowing the patient to preserve some level of realistic hope. The physician has a duty to help the patient understand, decide upon, and seek reasonable treatment should this be available and to help avoid ineffective or useless treatments.

1.6.2. Progressive Disorders. For progressive disorders the physician should provide or refer the patient to services that will help maintain or prolong the patient's autonomy and independence. When the patient's neuromuscular diagnosis is expected to limit the patient's life expectancy, the physician has a duty to provide this information to the patient as well as to provide a realistic estimate of life expectancy, if possible. The patient has a right to this information in order to be able to plan appropriately and address end-of-life issues. The physician should be prepared to counsel the patient regarding end-of-life issues and to provide to or refer the patient for this care as appropriate.

1.6.3. Treatment. Patients with neuromuscular disorders, many of which currently have limited treatment options, may seek out or request treatments that are not beneficial to the treatment of their disease. The physician cannot be required to provide medical treatment to a patient if the physician determines such treatment to be not beneficial medically or ethically inappropriate. If a physician's determination regarding medical care conflicts with the advance directive of a competent patient (or the treatment decision of the patient's surrogate), then the physician should explain his or her treatment determination and recommendations with the goal of resolving the conflict. If the conflict cannot be resolved and this interferes with the physician's care of the patient then the physician shall make a reasonable effort to find another physician who will provide care for the patient.

1.6.4. Pain Management. Many neuromuscular disorders can result in significant acute or chronic pain for patients with these diagnoses. Patients in pain have a legitimate right to access to pain management. Pain management is a complex area of patient care and one that has ethical implications for physicians. Physicians who elect to manage acute or chronic pain in this population should be familiar with the various pharmacologic and non-pharmacologic modalities and options available. Physicians who choose to manage their patients' acute or chronic pain must have a solid working knowledge of the dosing schedules, side-effects, and the diversion or abuse potential of the various medications available for pain management. Physicians should also be very familiar with the use of pain contracts, the various professional guidelines, and state or federal regulations related to the management of acute or chronic pain. Physicians who elect not to manage a patient's acute or chronic pain should refer the patient to another physician or pain specialist for this management as appropriate.

2. GENERAL PRINCIPLES OF PATIENT CARE

2.1. Professional Competence. The physician should perform evaluations only within the scope of his or her training, experience, and competence. The physician should provide care that represents the prevailing standard of care for neuromuscular and EDX practice.

Physicians should use only standard, well-accepted, and published techniques and methods of evaluation and interpretation. Evidence-based techniques are preferable. To this end, physicians should participate in, and keep documentation of, a regular program of continuing education. Physicians should maintain current technical skills, and ensure they have adequate experience before introducing new techniques into practice. On occasion, other new or non-standard techniques may be necessary when dealing with an unusual clinical problem or a research study. If all or part of the consultation is considered research, it must conform to the guidelines in Section 7.

2.2. Confidentiality. The physician must maintain patient privacy and confidentiality, both in performing EDX studies and the configuration of the examination areas in which they are performed, in accordance with all state and federal laws and regulations addressing patient privacy. The patient's name or other demographic information, as well as details of the patient's life or illness that would identify the patient, must not be publicized or published without written permission.

2.3. Patient Records. Physicians should keep and manage medical records that are complete, accurate, and in compliance with the Health Insurance Portability and Accountability Act (HIPAA). The physician's records should include a statement of the problem and the indications for the neuromuscular evaluation and/or the EDX study, description of the findings, assessment of normality or abnormality of these findings, and clinical correlation and diagnostic conclusions. Storing recordings of actual waveforms from nerve conduction studies (NCSs) and needle electromyography (EMG) is not required. Information within the medical records should be available only to appropriate individuals, including referring physicians, patients, and others with a valid release of information signed by the patient. Urgent information should be communicated directly and promptly to the referring physician, and appropriately documented in the physician's record.

2.4. Professional Fees. The physician is entitled to reasonable compensation for services commensurate with specified billing procedures, the comprehensive nature of the evaluation, difficulty of the study, time involved, and the number of procedures performed.

The fee structure must be made available upon request to patients, referring physicians, or third-party payers. The physician should bill for and receive compensation for only those services actually rendered or supervised. The physician must not receive a fee for making a referral or give a fee for receiving a referral ("fee-splitting"). The physician should not receive a commission from anyone for an item or service ordered for a patient ("kickback").

2.5. Appropriate Services. The physician should perform a sufficiently comprehensive neuromuscular evaluation and/or EDX study that can address the issues necessary to determine or evaluate a reasonable differential diagnosis. For the EDX study the physician must be involved in the pretest evaluation (focused history and physical examination) of the patient and the plan of the study, and should perform only those tests that are medically indicated. Tests selected and procedures used should conform to published guidelines, when available.

2.5.1. The physician has the ultimate responsibility for NCS examinations, even if they are performed by a technologist or another physician under the physician's supervision. The physician must be readily available and must promptly review and evaluate the results of the NCSs. The patient should remain in the examination room until the supervising EDX physician has reviewed the NCS results.

2.5.2. All needle EMG examinations should be performed by the appropriately trained neuromuscular or EDX physician, or, in the case of residents or fellows, under the direction of such a physician.

2.5.3. Except in unusual circumstances, the NCSs and EMG examination of a single patient should be performed on the same day, by the same EDX physician, for continuity and consistency.

2.5.4. The evaluation and diagnosis of neuromuscular disease may require the use of a number of specialized laboratory or diagnostic tests. The physician may have the appropriate training to perform some of these specialized studies. Referral to other specialists may be necessary for some of these specialized tests. Many of these tests may provide information that can pose ethical dilemmas for the physician as well as the patient, such as genetic testing. Genetic testing can be used to diagnose a genetic neuromuscular disease when there is only a family history, but no clinical findings present in the patient. Genetic testing can be used to test for the presence of a suspected gene in a patient's family members. Each type of testing carries the potential for different ethical dilemmas. Physicians should consult with experts in these areas to address issues of concern and follow any state or regulatory guidelines in this area. As the diagnosis and management of neuromuscular disease evolves, new ethical questions will continue to present themselves. Society's viewpoint on these topics also will continue to shift requiring the physicians to be ever vigilant.

3. PERSONAL CONDUCT

3.1. Respect for the Patient. The physician must treat patients with respect and honesty, with particular sensitivity to language barriers, sociocultural diversity concerning personal modesty (appropriate use of chaperones), physical pain, and disability. The physician must not abuse or exploit the patient psychologically, sexually, physically, or financially.

3.2. Respect for Agencies and the Law. The physician should observe applicable laws. The physician should cooperate and comply with reasonable requests from insurance, compensation, reimbursement, and government agencies within the constraints of patient privacy and confidentiality.

3.3. Maintenance of the Physician's Personal Health. The physician should strive to maintain physical and emotional health and should refrain from practices that may impair his or her ability to provide adequate patient care.

4. CONFLICTS OF INTEREST

4.1. The Patient's Interest Is Paramount. Whenever a conflict of interest arises, the physician must attempt to resolve it in the best interest of the patient. Conflicts of interest that cannot be eliminated should be disclosed to the patient. If, after discussing the conflict, the patient does not want to proceed, the physician should not perform the consultation on the patient.

4.2. Avoidance and Disclosure of Potential Conflicts. The physician must avoid practices and financial arrangements that would, solely because of personal gain, influence decisions on the types of consultations performed on patients. Financial interests of the physician that might conflict with appropriate medical care should be disclosed to the patient.

4.3. Healthcare Institutional Conflicts. The physician should advocate for his or her patient's medical interests when they are jeopardized by policies of a healthcare institution or agency. The physician

should inform the patient when referral restrictions on testing would limit the validity of results.

5. RELATIONSHIPS WITH OTHER PROFESSIONALS

5.1. Cooperation and Communication with Healthcare Professionals. Physicians should cooperate and communicate with other healthcare professionals, including other physicians, nurses, and therapists, in order to provide the best care possible to patients. Written and oral communication with other healthcare professionals should be carried out in a timely and courteous manner. The terms used in the communication should be useful to the referring physician and be as responsive to the referral question as possible.

The physician may teach fellows and residents how to perform the EDX consultation. Effective teaching requires close supervision of trainees during the actual testing and careful review of the report of the findings before it is sent to the referring healthcare professional.

On occasion, the physician, while evaluating a patient referred for EDX testing, will determine, based on available clinical information, that the patient most likely has a medical problem that is not localized within the peripheral neuromuscular system. The physician should attempt to communicate this opinion to the referring healthcare professional with the goal of optimizing further care for this patient. Options may include not proceeding with the planned EDX testing and redirecting the diagnostic evaluation.

5.2. Referrals from Other Physicians. For the most part, referrals to physicians come from other physicians. Referrals for neuromuscular evaluations and or EDX testing may come from other healthcare professionals and lay-persons, however, and patients may refer themselves. If the referral did not come from another physician, every attempt should be made to identify the patient's primary physician so that the report of the results of the neuromuscular or EDX consultation may be sent to that physician if the patient consents. If the patient has no primary care physician, then the physician should refer the patient to a primary physician or specialist if one is needed.

If the primary care or referring physician agrees, the physician may actively participate in further evaluation and treatment of the patient's neuromuscular problems and may even become the principal provider of the care for these problems.

5.3. Studies Performed on One's Own Patients—Self-Referral. Most physicians see and follow patients for clinical, diagnostic, and therapeutic reasons. In the course of providing such evaluation and management, a physician may find it necessary for these patients to have EDX or other specialized studies, such as biopsies or ultrasound, to clarify a diagnosis or assist with treatment. Ordering and performing EDX studies or any other specialized studies one's self, for which the physician is appropriately trained and experienced to do, on one's own patient is not considered a "self-referral," but instead part of the consultation, and considered to be appropriate patient care. In fact, it may be in the best interest of the patient for the physician, who knows the patient, to perform these studies. When considering performing EDX or other specialized studies on one's own patient, the physician must keep in mind that there must be a proper indication for the study, which is consistent with relevant guidelines. The need for and the scope of the study should be properly documented in the patient's medical record. Some neuromuscular and EDX physicians may prefer to refer their patients to other physicians for specialized or EDX testing, to avoid even the appearance of a conflict of interest. Patients also always retain the right to request specialized neuromuscular or EDX testing by an independent physician without compromising their ongoing clinical care.

5.4. Peer Review, Utilization Review, and Quality Assurance. The physician should participate in peer review, utilization review, and quality assurance activities in order to promote optimal patient care.

5.5. Competence of Colleagues and Impaired Physicians. Physicians should not knowingly ignore a colleague's incompetence or professional misconduct, thus jeopardizing the safety of the colleague's present and future patients. The physician should strive to protect the public from an impaired physician and to assist in the identification and rehabilitation of impaired colleagues. Physicians should cooperate with peer review processes.

5.6. Expert Witness Testimony. Physicians, as a matter of acting in the public interest, are encouraged to serve as impartial expert witnesses in clinical and technical matters regarding electrodiagnostic and neuromuscular medicine. Expert witness testimony is opinion testimony that may relate to the standard of care, nature and extent of disability, causation of injury, clinical status of the patient, or prognosis. Physicians cannot be required to provide expert witness testimony. An expert testifies either for the person bringing the case (the plaintiff or the government in a criminal matter), the person being sued (the defendant), or the judge. It is important for physicians acting as expert witnesses to remember that transcripts of depositions

and courtroom testimony are public records, and subject to independent peer reviews.

5.6.1. The minimum statutory requirements for qualifications for an expert witness in a medical malpractice action should reflect the following:

(a) The witness should have comparable education, training, appropriate certification, and occupational experience in the same field of expertise as the defendant.
(b) The witness's occupational experience should include active medical practice or teaching experience in the same field of expertise as the defendant.
(c) The witness's active medical practice or teaching experience must have been within 5 years of the occurrence giving rise to the claim.

5.6.2. It is unethical for expert witnesses to provide services under a contingent fee arrangement or to link compensation to the outcome of the case. Compensation should be reasonable and commensurate with actual services rendered.

5.6.3. Physicians providing expert medical testimony should be adequately versed in the medical and scientific issues involved in the matter and, before giving testimony, should carefully review the relevant records and facts of the case and the standards of practice prevailing at the time of the occurrence that gave rise to the claim.

5.6.4. Physicians should testify about the medical records, the standard of care, and any other matter related to the case fairly, honestly, and in a balanced manner.

5.6.5. Physician expert witnesses are expected to be impartial and should not adopt a position as an advocate or partisan in the legal proceedings.

5.6.6. Compensation should be reasonable and commensurate with actual services rendered.

5.7. Healthcare Organizations. The physician may enter into contractual agreements with managed healthcare organizations, prepaid practice plans, or hospitals. The physician should retain control of medical decisions without undue interference. The patient's welfare must remain paramount.

6. RELATIONSHIPS WITH THE PUBLIC AND COMMUNITY

6.1. Public Representation. Physicians should not represent themselves to the public in an untruthful, misleading, or deceptive manner regarding qualifications, credentials, and expertise through statements, testimonials, photographs, graphics, or other means. A patient's medical condition must not be discussed publicly without his or her consent (see Section 2.2).

6.2. Duties to Community and Society. Physicians should work toward improving the health of all members of society. This may include participation in educational programs, research, public health activities, and the provision of care to patients who are unable to pay for medical services. The physician should be aware of the limitation of society's healthcare resources and should not squander those finite resources by performing unnecessary tests. The needs of an individual patient should be given priority.

6.3. Existing Laws. The physician shall be obligated to obey the laws of the land and refrain from unlawful activities, but is strongly encouraged to help produce change in laws that are not in the best interest of patients and society. Physicians should cooperate with legal authorities and processes. They should honor reasonable requests from insurers and government agencies, consistent with ethical and legal privacy protections required by law.

7. CLINICAL RESEARCH

7.1. Informed Consent. Research is an activity designed to develop and increase generalized knowledge. All research must be approved and in compliance with current IRB rules. Informed consent must be obtained for all research on human subjects. A full disclosure of risks, as well as benefits, must be specified. In all circumstances pertaining to research, informed consent must include a written document signed by the subject. The physician or other appropriately identified investigator is responsible for obtaining informed consent from the research subject for any research investigation or clinical trial. If the subject is an active patient of the physician-investigator, the physician must recognize there is a potential that the patient, because of the dependent relationship/position to physician-investigator, may feel under duress to consent to the research whether or not this is expressed. To avoid any real or perceived duress, it is advised that, whenever possible, the informed consent be obtained by an investigator completely independent of the physician–patient relationship. Special care should be taken with vulnerable populations, including children, pregnant women, cognitively impaired individuals, prisoners, and others. The refusal of the patient to participate should not interfere with the patient–doctor relationship.

7.2. Institutional Review. The research project should conform to generally accepted scientific principles. The physician who participates in clinical research must ascertain that the research has been approved by an IRB or other comparable

body, and must adhere to the requirements of the approved protocol. Any adverse events or outcomes must be documented and reported to the IRB and sponsoring and regulatory agencies as required.

7.3. Financial Charges to Research Subjects. Although it is acceptable to mix clinical practice and clinical research procedures in the same setting, the research procedures should be clearly identified in the IRB-approved research protocol. Compensation for clinical research should follow applicable study guidelines. Physicians should not bill the patient or the insurer for services already compensated by the study sponsor. All federal, state, and local regulations pertaining to billing for clinical care/services associated with clinical research must be observed.

7.4. Disclosure of Potential Conflicts. The physician who is paid for testing patients in a clinical research project should inform the patient of any compensation he or she receives for the patient's participation. The compensation for patient testing should be reasonable in amount.

7.5. Reporting Research Results. The physician should publish research results—both positive and negative—truthfully, completely, and without distortion. In reporting research results to the news media, the physician should make statements that are clear, understandable, and supportable by the facts. Physicians should not publicize results of research until after the data have been subjected to appropriate peer review.

APPENDIX: AMERICAN MEDICAL ASSOCIATION PRINCIPLES OF MEDICAL ETHICS[1]

Preamble. The medical profession has long subscribed to a body of ethical statements developed primarily for the benefit of the patient. As a member of this profession, a physician must recognize responsibility to patients first and foremost, as well as to society, to other health professionals, and to self. The following principles adopted by the American Medical Association are not laws but rather standards of conduct that define the essentials of honorable behavior for the physician.

Principles of Medical Ethics

I. A physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights.

II. A physician shall uphold the standards of professionalism, be honest in all professional interactions, and strive to report physicians deficient in character or competence, or engaging in fraud or deception, to appropriate entities.

III. A physician shall respect the law and also recognize a responsibility to seek changes in those requirements that are contrary to the best interests of the patient.

IV. A physician shall respect the rights of patients, colleagues, and other health professionals, and shall safeguard patient confidences and privacy within the constraints of the law.

V. A physician shall continue to study, apply, and advance scientific knowledge; maintain a commitment to medical education; make relevant information available to patients, colleagues, and the public; obtain consultation; and use the talents of other health professionals when indicated.

VI. A physician shall, in the provision of appropriate patient care, except in emergencies, be free to choose whom to serve, with whom to associate, and the environment in which to provide medical care.

VII. A physician shall recognize a responsibility to participate in activities contributing to the improvement of the community and the betterment of public health.

VIII. A physician shall, while caring for a patient, regard responsibility to the patient as paramount.

IX. A physician shall support access to medical care for all people.

Adopted by the AMA's House of Delegates, June 17, 2001.

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