



2025 Mission MSA Centers of Excellence Handbook

Policies and Procedures for
Designation

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Mission MSA Contact Information

Website: missionmsa.org

Staff Email: jessie.iregui@missionmsa.org

Telephone: +1-866-737-4999

Postal Mail:

Mission MSA

1660 International Drive

Suite 600

McLean, VA 22102 USA

Office hours: Monday through Friday 8:30 a.m. – 5:00 p.m. (08:00 – 17:00) U.S. ET

About Mission MSA

For over 30 years, Mission MSA (formerly The MSA Coalition) has been a leading resource on multiple system atrophy. With a dedicated staff and volunteer board of directors, Mission MSA is a team dedicated to driving progress in multiple system atrophy. From cutting-edge research and medical education to strategic fundraising, seamless operations, and impactful marketing, they unite to support those affected, fostering hope, and advancing understanding.

OUR MISSION

Mission MSA is devoted to improving quality of life and building hope for people affected by multiple system atrophy through:

- Providing patients and care partners with trusted and compassionate emotional **support**.
- **Educating** patients, care partners, and healthcare professionals with credible, critically important, and relevant information.
- Building a sense of **community** by connecting and unifying people affected by MSA.
- Funding patient-centric collaborative **research** aimed at alleviating symptoms, slowing disease progression, and discovering a cure.
- Playing a leading role in raising awareness and **advocating** for those impacted by the disease.

OUR VISION

Improve quality of life for the multiple system atrophy community by expanding access to care and support while advancing research toward treatment and a cure.

The Purpose and Value of COE Designation

Multiple System Atrophy (MSA) is a rare but devastating, progressive neurological disorder characterized by a variable combination of symptoms including parkinsonism, cerebellar and pyramidal tract signs, and autonomic dysfunction. As the name of the disorder alludes, MSA can affect multiple systems including blood pressure/cardiovascular, urogenital, gastrointestinal, sleep, pulmonary, psychiatric, and even cognition. For any one patient and their care partner(s), this multitude of symptoms can be overwhelming and requires a dedicated interdisciplinary team and requires a coordinated effort – “a village” – and support system. MSA interdisciplinary clinical care should ideally include exemplary sub-specialty care, support services, education, outreach, and research opportunities for MSA patients, care partners, and family members.

The goal of the MSA Center of Excellence (COE) program is to provide access to the best possible and easily accessible multi-disciplinary clinical care and supporting services for individuals affected by Multiple System Atrophy (MSA) and their families through a geographically diverse network of local and/or regional clinical centers. In addition to coordinating care with both clinical and social services, the Centers will provide professional and lay education in the areas they serve, will be involved in, and inform patients of MSA clinical research, and collaborate with Mission MSA in its efforts to continually improve the lives of those affected by MSA.

The vision of Mission MSA is to create the standard of care in the United States in which patients, care partners, and their families are referred to MSA COEs that will provide the necessary sub-specialty expertise. Within these COEs, a multidisciplinary team will coordinate care to ensure those impacted by MSA receive a comprehensive, gold-standard, continuum of care.

Designation Process

Activity	Dates
Application Release	Sept 9, 2024
Due Date	Oct 20, 2024
Internal Review	Oct 21-Dec 2, 2024
Centers Notified	Dec 6, 2024
Terms & Agreements Due	Jan 31, 2025
2025 MSA COEs Press Release	Feb 2025

Step 1 - Prepare and Submit Full Application

Prospective Centers will submit a full application to Mission MSA for review.

The following information will be required:

1. **Region and population:** Describe the area/region and population that is currently served and any potential changes that may result from the presence of MSA COE.
2. **Description of the MSA clinic:** Provide information including history, location, frequency, billing, accepted insurance, arrangements for seeing patients without means, and typical follow-up frequency.
3. **Clinical Services:** Describe how access to each service is provided. Elaborate on the strengths and weaknesses of the clinic, future goals, and what changes, if any, would occur as a result of becoming a MSA COE. If your clinic offers telemedicine, provide a brief description of the program and use.
4. **Outreach:** Describe efforts to help extend services to additional patients, families, care partners, and allied health providers.
5. **Education:** Describe how your team contributes to educating healthcare professionals, MSA families/care partners, and the public.
6. **Administration:** Provide specific information about your proposed Clinic Director, Social Worker, and Center Operations Team, including names and contact information.

7. **Supporting Material:** Include the following – curriculum vitae of core Center personnel, a list of members of your multidisciplinary team and information about additional on campus providers to whom you refer MSA patients.
8. **Budget:** Provide a budget with specific justifications for each budget item. Major categories include personnel, services, supplies, and travel. Personnel should include a percentage of effort and a breakdown of base pay and fringe benefits.
9. **Other support and institutional commitment:** Describe other support for your MSA Center, including grants or donations that cover salaries, administrative support and/or space. For initial applications, include a Letter of Support from your Department Chair.
10. **Terms and Conditions:** Agree to the terms and agreements outlined by the Mission MSA COE Program. Return signed terms and agreements, handbook, wire transfer form, and W9 (if applicable), by an official authorized to sign on behalf of the institution, to Mission MSA by published deadline.

Step 2 – The Review Process

Each application will be reviewed by Mission MSA. All applications will be scored with the following five individual criteria:

1. The quality of the overall application and proposed services provided
2. Regional/geographic diversity
3. Unique offerings or characteristics that add to the MSA clinic
4. Use of funds and proper distribution of budget
5. MSA community activity and research

Each designated Center agrees that Mission MSA, its staff, and its advisors, reserve the right to approve or reject any applications.

Step 3 – Awarding Designated COEs

COE designation will be valid from January 1, 2025, to December 31, 2025.

Applicants will be notified by e-mail after a designation decision has been made by the COE Advisory Board. An award letter will be sent to the Center's clinical director(s). If not selected, the letter will detail areas for improvement to enhance future applications.

Selected applicants will be sent an award packet with the following documents to be completed by the date requested by Mission MSA:

- COE Handbook
- Terms and Agreements
- W-9 Template (if applicable)
- Bank information template

Awarded MSA Centers of Excellence will receive an annual restricted gift of \$5,000 per year during the designation period. COEs are eligible, at time of application, for additional educational event funding of \$2,500 per year for in-person educational events for healthcare providers and/or patients and care partners.

Funding and awards will be contingent on receipt and review of applications and annual progress reports. Renewals will occur annually and will require completion of renewal applications.

Mission MSA reserves the right to suspend the Center of Excellence designations and grant funding for failure to deliver services or adhere to the terms and conditions delineated in the letter of award.

- Identified deficiencies should be addressed within 90 days of suspension or the Center of Excellence designation will be revoked, and grant terminated.

Terms and Agreements

The MSA Centers of Excellence Terms and Agreements sets forth the requirements for use and display of the MSA Centers of Excellence designation. All designated sites are required to sign and conform to the terms and agreements. Failure to do so may result in actions up to and including revocation of the designation.

MSA Centers of Excellence are required to participate in a minimum of 1 Mission MSA patient-facing educational resource per year, which may consist of:

- Webinars, presentations at patient conferences or International MSA Congress, collaboration for resource development (brochures, one-pagers, whiteboard videos, etc.)

MSA Centers of Excellence are to adhere to the marketing guidelines provided by Mission MSA in the COE Toolkit.

MSA COE Appeals Panel

The MSA COE Appeals Panel is the body given authority to review and consider all alleged violations of the MSA Centers of Excellence Institute Terms and Agreements by designated sites. The Medical Advisory Board is comprised of 4-6 representatives from Designated COE sites in good standing, appointed by Mission MSA.

Violations of Centers of Excellence Terms and Agreements

The Centers of Excellence program defines very clear criteria and procedures for addressing reported or alleged violations of the terms and agreements by designated sites and corresponding disciplinary actions. These policies and disciplinary actions are set forth to ensure the program's credibility and advance the industry's standards.

- Designated COEs agree to be bound by the COE Terms and Agreements
- Designated COEs must sign and comply with the COE Terms and Agreements and these Procedures for Alleged Violations
- Designated COEs will not, in any way, attempt to persuade, induce, or coerce another COE to breach the COE Terms and Agreements, and acknowledge and agree that inducing a breach is to be considered a violation of the same.
- Designated COEs will be responsible for any violation by their agents, representatives, and employees if the MSA COE Appeals Panel finds, after considering all the facts and circumstances, that the responsible member has authorized, condoned, or supported such a violation, or in any other way failed to prevent a violation from occurring where the responsible member had actual knowledge of the violation.

Policies and Procedures for Alleged Violations

The policies and procedures for alleged violations of the Centers of Excellence Terms and Agreements and directions for submitting a complaint are as follows:

Submitting a Complaint

All complaints **MUST** be filed **IN WRITING** and signed by an authorized official of the complaining party (*Complainant*).

Should Mission MSA receive an inquiry or complaint by phone, mail, or in person, staff will inform the Complainant of procedures to officially file a complaint. It may be that an individual is simply making an inquiry as to clarification of a policy or procedure, in which case staff may provide guidance and resolve the issue. In this case the inquiry

would not be considered an official complaint. Should staff determine based on the information provided that an actual procedure may have been violated the Complainant will be so advised and instructed to submit a written complaint.

It is the Complainant's responsibility to submit a formal, written complaint to Mission MSA. If no written complaint is received within thirty (30) days, no further action will be taken on behalf of the Complainant.

The written complaint must state with specificity the section of the Terms and Agreements that the COE is alleged to have violated, and include all data, allegations, information, or documentation supporting the allegation. The Complainant shall include a statement granting a limited waiver of confidentiality to allow the members of the MSA COE Appeals Panel to fully investigate the complaint.

The MSA COE Appeals Panel will advise the Complainant that any information pertaining to the complaint may be provided to concerned parties, including, but not limited to, members of the MSA COE Appeals Panel, the potential witnesses, the accused member (*Respondent*) and, if necessary, members of the Board of Directors. The Complainant will be advised that refusal to waive confidentiality may impede the investigation conducted by the MSA COE Appeals Panel.

Should a complaint be filed directly against Mission MSA and/or its staff members, the complaint will be immediately assigned to the MSA COE Appeals Panel. The Appeals Panel will then take full responsibility for processing the complaint and handling all administrative aspects involving the Formal Complaint Procedure.

Acknowledgement and Responses

If it is determined by the Appeals Panel review that the complaint is valid, Mission MSA staff will notify the Respondent COE of the complaint with any appropriate documentation and that he/she has thirty (30) days to file a formal response to the complaint. The Respondent may respond to the allegations in the complaint, which should include all data, information, and documentation supporting its position. A description of corrective measures taken or intended to be taken may be included. Failure by the

Respondent to provide a response within thirty (30) days will result in a default judgment with no right of appeal. The response will be reviewed by the MSA COE Appeals Panel and shared with the Complainant.

Determination

Once the MSA COE Appeals Panel has received a response and any documentation from the Respondent, the MSA COE Appeals Panel may investigate anything contained in the documentation at its sole discretion. This may be assigned to one member of the MSA COE Appeals Panel or to the entire MSA COE Appeals Panel. The MSA COE Appeals Panel may, at its sole discretion, hold a hearing under the terms and conditions it deems appropriate. Within thirty (30) days of receiving the response, or, if a hearing is held, within 30 days of the hearing, the MSA COE Appeals Panel will make a determination on the matter. All members of the MSA COE Appeals Panel will have a vote. The MSA COE Appeals Panel may determine that a violation has occurred only upon a finding of clear and convincing evidence by a unanimous vote of the MSA COE Appeals Panel.

If the MSA COE Appeals Panel determines that a violation has occurred, the MSA COE Appeals Panel will then decide by majority vote as to the sanction to be imposed. The determination will then be mailed to all parties via certified mail, return receipt, or overnight delivery with signature confirmation and receipt. Whatever the outcome of the determination, either party will have the right of appeal under Section 4.

Accepting Judgment

Either party will have the right, within fifteen (15) days of receiving an MSA COE Appeals Panel decision, to request a further review which will be conducted by T Mission MSA Executive Committee. If neither party files an appeal within fifteen (15) days, the decision of the MSA COE Appeals Panel will be final. The Respondent and the Complainant will each have the right to be represented by their own legal counsel.

Board of Appeals Procedure

The proceedings before the Executive Committee will be based on written submissions by the interested parties per the schedule set forth below.

To initiate an appeal, the appealing party will file a notice of appeal and supporting brief specifically stating the grounds for appeal. The MSA COE Appeals Panel will then provide, within thirty (30) days, the entire record of all information and proceedings to the Executive Committee. The responding party will have thirty (30) days from the filing of the appeal to provide a response brief to the Executive Committee. The Executive Committee will conduct the appeal process and may solicit further information from any and all parties involved. All correspondence will be delivered to Mission MSA headquarters via certified

mail, return receipt requested, or overnight delivery. Mission MSA headquarters staff will compile the appeals information from both parties for Executive Committee review.

The Executive Committee will consider the appeal at its next meeting held after the reply submission is filed. All matters heard on appeal will be submitted in a written presentation. If the Executive Committee deems it necessary, it will hear oral presentations by the parties. The Executive Committee will render a final determination within thirty (30) days following the meeting at which the appeal is addressed. A unanimous vote of the Executive Committee finding that the MSA COE Appeals Panel decision was clearly erroneous is necessary to overturn a determination of the MSA COE Appeals Panel. The decision of Mission MSA Executive Committee will be final.

The Executive Committee will notify the Complainant and the Respondent of the Executive Committee's determination and any recommendations within twenty-four (24) hours of the final decision.

Any cost related to this arbitration process shall be paid in full by the designated COE.

Sanctions

If it is determined that grounds exist to take disciplinary action against a designated COE, one or more of the following actions may be taken or such other action(s) as the MSA COE Appeals Panel may deem appropriate:

1. Require the COE to engage in remedial education and/or training;
2. Suspend the COE's designation for a period of time and/or require the COE to participate in a mandatory audit of continuing education for a period of time;
3. Deny a designated COE application for reaccreditation for a period of time;
4. Notify other legitimately interested parties of findings and disciplinary action.

Complaint Filing

All complaints should be filed IN WRITING and signed by an authorized official of the complaining party. The following items must be submitted in order for Mission MSA to review and process your complaint:

- Formal, written complaint and supporting documentation
- A brief statement on how this complaint directly relates to a violation of The MSA Centers of Excellence Terms and Agreements

All documentation listed above should be submitted directly to:

jessie.iregui@missionmsa.org and info@missionmsa.org

