

MDF Awareness Ambassador Speaking Engagement Requests & Terms

Purpose

The Myotonic Dystrophy Foundation (MDF) Awareness Ambassador program connects trained volunteer speakers with opportunities to share lived experience with myotonic dystrophy (DM) in support of MDF's mission of Community, Care, and Cure. MDF Awareness Ambassadors may speak to a variety of audiences, including healthcare professionals, academic researchers, pharmaceutical and biotechnology companies, policymakers, and community groups.

This document outlines the terms under which an institution, organization, or company may request and host an MDF Awareness Ambassador for a speaking engagement.

1. Engagement Requests and Coordination

All requests to engage an MDF Awareness Ambassador must be submitted through and coordinated by MDF. MDF will determine whether an engagement is an appropriate fit based on the purpose of the request, the intended audience, the Ambassador's experience, speaker availability, and alignment with MDF's mission and values.

An institution, organization, or company may not contact, book, or schedule an MDF Awareness Ambassador directly for a DM-affiliated speaking engagement unless expressly authorized in writing by MDF.

MDF reserves the right to decline, postpone, or withdraw from any speaking engagement request at its discretion, including when an engagement is not aligned with MDF's mission, does not provide adequate lead time or speaker support, or raises concerns related to speaker wellbeing, safety, or appropriate use of the Awareness Ambassador role.

2. Scope of the Engagement

Approval of one speaking engagement does not create ongoing open-ended, or preferred access to an MDF Awareness Ambassador.

Each speaking engagement is a separate arrangement that must be individually requested and approved by MDF. If the requesting institution, organization, or company wishes to invite the same MDF Awareness Ambassador to participate in a future event,

advisory activity, consultation, interview, panel, training, research-related discussion, internal meeting, or any other follow-up engagement, that request must be submitted to MDF as a new request and may not be arranged directly with the MDF Ambassador.

Unless MDF provides written approval in advance, the requesting institution, organization, or company may not treat an introduction to or participation by an MDF Awareness Ambassador as permission to:

- Contact the Ambassador for additional engagements outside the approved event;
- Add the Ambassador to a speaker roster, advisory pool, or ongoing consultant list;
- Invite the Ambassador to future internal or external meetings, interviews, or events;
- Request off-the-record follow-up conversations, strategic input, or patient insight outside the approved scope; or
- Use the Ambassador's participation as an endorsement of the institution, organization, or company, its products, pipeline, services, policies, or positions.

3. Role of the MDF Awareness Ambassador

MDF Awareness Ambassadors are trained volunteers who share personal experiences to increase awareness and understanding of myotonic dystrophy and the lived impact of the disease. They are not acting as employees, agents, contractors, clinical experts, medical advisors, or spokespersons authorized to speak on behalf of MDF beyond the scope of their lived experience and MDF-approved role.

MDF Awareness Ambassadors speak from their own personal perspective and experience. Their remarks should not be interpreted as medical advice, legal advice, scientific guidance, investment advice, or an official statement of MDF policy unless expressly stated by MDF in writing.

4. Engagement Content and Audience Alignment

MDF works with Awareness Ambassadors to prepare for speaking engagements and to tailor their remarks to the audience and purpose of the event. Requesting institutions, organizations, or companies should provide MDF with sufficient information about the event so MDF and the speaker can prepare appropriately, including:

- event title, format, and date;

- sponsoring organization and intended audience;
- topic, objectives, and desired outcomes;
- expected length of the engagement;
- whether the engagement is live, virtual hybrid, recorded, or media-facing;
- whether there will be Q&A, panel discussion, or moderation;
- whether materials, talking points, or prompts will be provided; and
- any honorarium, travel, accessibility, or logistical arrangements.

MDF may request an agenda, draft questions, or a short briefing in advance, particularly for media, industry, legislative, research, or healthcare-facing engagements.

5. Honorarium and Payment

MDF strongly prefers that all honoraria and related speaker payments be paid to MDF, and that MDF then distribute payment to the MDF Awareness Ambassador in accordance with MDF's internal processes.

Unless otherwise approved in writing by MDF in advance:

- the requesting institution, organization, or company will remit the agreed-upon honorarium to MDF, not directly to the MDF Awareness Ambassador;
- MDF will be responsible for issuing payment to the Awareness Ambassador;
- MDF may invoice the institution, organization, or company directly for the honorarium and any approved travel related expenses;
- no payment terms may be changed directly with the MDF Awareness Ambassador; and
- reimbursement for travel, lodging, meals, or other approved costs must be coordinated through MDF.

If an institution, organization, or company requires direct payment to the MDF Awareness Ambassador due to internal compliance or accounts payable requirements, that arrangement must be disclosed to and approved by MDF in advance. MDF reserves the right to decline an engagement if the proposed payment structure does not align with MDF's policies or creates an administrative, legal, or ethical concern.

6. Travel, Expenses, and Accessibility

If travel is required, all travel expectations, reimbursement terms, and accessibility needs should be discussed with MDF in advance and confirmed before the engagement is finalized. No travel should be booked directly with the MDF Awareness Ambassador unless MDF has approved that arrangement in writing.

The requesting institution, organization, or company, is expected to work with MDF to support reasonable accessibility needs, scheduling limitations, and accommodations necessary for the MDF Awareness Ambassador's full participation.

7. Use of Name, Likeness, and Materials

The requesting institution, organization, or company may reference the MDF Awareness Ambassador's participation only for the limited purpose of promoting or documenting the specific approved engagement, unless MDF provides separate written permission for additional use.

Without MDF's prior written approval, the institution, organization, or company may not:

- record, distribute, publish, or repurpose the MDF Awareness Ambassador's presentation, remarks, image, or likeness beyond the approved event use;
- quote the MDF Awareness Ambassador in promotional, investor, commercial, public relations, advocacy or marketing materials;
- use the MDF Awareness Ambassador's name, image, or statements to imply endorsement of the institution, organization, or company, a therapy, a product, a service, a clinical trial, or policy position; or
- share the MDF Awareness Ambassador's contact information with third parties.

If recording, photography, transcription, or post-event distribution is planned, that must be disclosed to MDF in advance and approved in writing before the engagement.

8. Speaker Wellbeing and Scheduling

MDF Awareness Ambassadors are volunteers, all of whom are living with DM or are caregivers. Health, caregiving responsibilities, accessibility, and personal wellbeing may affect scheduling and participation. MDF reserves the right to substitute a different speaker, reschedule an engagement, or withdraw an MDF Ambassador if circumstances require.

MDF will make reasonable effort to communicate changes promptly and to identify an alternative solution where possible.

9. Organizational Expectations

By submitting a request for an MDF Awareness Ambassador and/or proceeding with an approved engagement, the requesting institution, organization, or company agrees to:

1. Work through MDF as the sole coordinator for the engagement.
2. Provide accurate and timely information about the audience, purpose, format, and expectations for the event.
3. Respect the limited scope of the approved engagement.
4. Refrain from contacting the MDF Awareness Ambassador directly for future or additional engagements unless authorized by MDF.
5. Coordinate honoraria, expenses, and logistics through MDF unless MDF approves another arrangement in writing.
6. Use the MDF Awareness Ambassador's story, participation, and likeness respectfully and only as authorized.
7. Avoid representing the MDF Awareness Ambassador as an employee, consultant, or official spokesperson for MDF or the institution, organization, or company beyond the approved engagement.
8. Comply with any additional written instructions provided by MDF related to scheduling, accessibility, logistics, confidentiality, or event conduct.

9. MDF Contact

All speaking engagement requests, follow-up requests, payment coordination, and questions regarding MDF Awareness Ambassador participation should be directed to:

Myotonic Dystrophy Foundation

Mindy Buchanan, Director of Programs

Email: mindy.buchanan@myotonic.org

Phone: +1-415-800-7777