

Jul 20, 2026

EGMEDC Executive Board

Minutes for Signature

Invited: Alessia Cavazza, Cecilia Jiménez Mallebrera, Ellen Koekoeckx, Özcan Met, Jens-Ole Bock, Emmanuel Mussault, Clarissa Braun (Secretariat)

Attended: Cecilia Jiménez Mallebrera, Ellen Koekoeckx, Emmanuel Mussault, Clarissa Braun (Secretariat)

Purpose: Website and Content Development, Clinical Trials and Partnerships, Operational and Administrative Processes

Key Decisions Approved

- **Membership type definitions:** Membership type definitions, including benefits and expectations, are set to be revisited and discussed further prior to the website launch in the next Board Meeting.
- **Canada partnership engagement:** The Board approves exploring a collaboration with the Canadian rare disease community, agreeing to schedule an introductory meeting with Jida El Hajjar, Ph.D. during the week of August 24th.
- **Partner meeting commencement scheduled:** The monthly partner member meetings are scheduled to begin in September to account for summer vacation periods.

Summary of Action Items

- **Secretariat:** Distribute previous and current Meeting Minutes to all participants. Email attendees regarding the upcoming two Board Meetings and vacation leaves, and further discuss postponing meetings if necessary. Inquire Jens-Ole about specific partner criteria and membership requirements via email. Forward these relevant partnership materials to Ellen for internal organization review. Work on adjusting and finalizing the EGMEDC website content for the public with today's input from the Executive Board and subsequent content verification by the Advisory Board. Place the Conflict of Interest Statement publicly available on the EGMEDC website. Send ERDERA Statement of Intent Form (including open text fields and updated details) after approval by the Executive Board via email to confirmed partners. Share Reimbursement Form again to the Executive Board and contact Özcan and Jens-Ole to inquire about their availability for acting as the treasurer and managing reimbursement signatures. Schedule meeting for Canadian Partnership Opportunity (EGMEDC x CANADA) in a timely manner.
- **Cecilia Jimenez, Ellen Koekoekx and Emmanuel Mussault:** Review input for membership section to build up in a reasonable way for the website and who would take the lead on this for the next Board Meeting.

Audit trail

Details

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Secretariat sent a signature request to:
Cecilia Jiménez Mallebrera
Ellen Koekoekx
Emmanuel Mussault
Clarissa Braun (Secretariat)

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COMPLETED
This document has been signed by all signers and is complete
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