

Aug 3, 2026

EGMEDC - Board Meeting

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 Approval, Clinical Trials and Partnerships, Membership Classification Frameworks

Key Decisions Approved

- **Website terminology revision requirements and silent launch:** Discussion of correct terminology for the website content to ensure scientific accuracy. Website approved by the Executive (here and via mail) and Advisory Board (via mail). specifically evaluating the differences between 'gene therapy', 'gene editing', and 'genome editing'. The website will remain password-protected for the Executive Board, Advisory Board, and partners, for the next days before a wider public release.
- **August 17th board meeting cancellation:** The Board Meeting scheduled for August 17th is cancelled due to the unavailability of many members.
- **Lead Membership structure:** Ellen Koekoeckx will take the lead on the discussion of Membership structure within the website and options can be revisited in the next Board Meeting.
- **Follow-up on potential collaborations:** Cecilia and Özcan will review mentioned collaborator options and reach out.

Summary of Action Items

- **Secretariat:** Enable public access to website by removing password protection (after text adjustments and the legal document updates are finalized) from the production website. Update newsletter drafts for approval by end of August. Discuss signup process for members and partners for the future with Jens-Ole and in the next Board Meeting. Schedule Joint Meeting for ERDERA partners end of August/beginning of September. Schedule new meeting date for Jida (EGMEDC x Canada) on August 27th or 28th.
- **Özcan:** Provide collaborator details: Share contact information for the research collaborator at the Red Blood Cell Center with Cecilia. This facilitates potential future partnerships within the consortium. Review the reimbursement documentation.
- **Ellen:** Taking on the Lead for Member Structure: Define the membership categories and requirements for patients, industry, and academia. Develop the structure and discuss it in the next Board Meeting.
- **Cecilia:** Summarize and communicate any key conclusions or action plans from the potential ERDERA partners latest in the next Board Meeting.

Audit trail

Details

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Secretariat sent a signature request to:

Ellen Koekoekx

Özcan Met

Cecilia Jiménez Mallebrera

Clarissa Braun (Secretariat)

2026/08/26

14:24:03 UTC

COMPLETED

This document has been signed by all signers and is complete

2026/09/08

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