Rare Diseases Ireland
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January 24 2026

2025 Annual General Meeting

Annual General Meeting - Minutes

Time: 12.30 pm, Oct 20, 2025

Venue: On-line via Zoom

In Attendance:

Board of Directors (Trustees): J McCormack (acting Chair), M Hennessy (Treasurer), A Micks, L Egan, A Daly, S O'Reilly, S O'Connell, F Griffin

RDI: Vicky McGrath (CEO), Lucy Collins Stack (RPM)

RD Community:

Aileen Timmons, Alana Ward, Andrew Olaye, Anne Lawlor, Anthony Morris, Ariadna Tigri, Brona Kearney, Caroline Dooley Martyn, Catherine McGrath, Catherine Quinlan, Cheryl Flanagan, Darran Brennan, Denise Dunne, Edwina Wrenn O'Connell, Finbarr Roche, Gemma Daina, Geraldine Sweeney, Harriet Doig, Ian Fahey, Jason Dabek, Laura Brady, Lesley Perkin, Lora Ruth Wogu, Lyndsey Walsh, Maeve Healy, Maria Panza, Mariam Prasad, Mary Boushel, Mary Kearney, Maureen Mason, Maureen Sweeney, Melissa Kinch, Miriam Buqueras Sanchez, Nicola Forbes, Padraig O Sullivan, Patricia O'Sullivan Lacy, Patricia Towey, Patrick J Moloney , Philippa Quigley, Ronan Donelan, Sandra Phair, Sarah Governey, Sharon Harris, Tamara Belecan, Timur Narbekov, William Rickard

Minutes

- No conflicts to declare
- Welcome from John McCormack, Acting Chair RDI – thanks to RD community for sharing their time with RDI
- Approval of Agenda – approved via show of hands
- 2024 AGM minutes – F Griffin propose & A Micks second
- 2024 Accounts presented by MH Financial position strengthening.
    - Accounts approved – L Egan propose & A Lawlor second
    - Auditor reappointment – A Daly propose & P Towey second

DRAFT - FOR APPROVAL

- Board renewal
    - Michael Blighe, Laura Egan & Avril Daly retired.
    - Thanks to Michael for his service.
    - Laura Egan & Avril Daly eligible for re-election - A Micks proposed, F Roche second.
- Overview of 2024/25 achievements provided by VM
    - Reminded all of RDI vision and membership criteria
    - Continuing to grow awareness
        - Rare Disease Day driving awareness amongst all stakeholders
        - Media engagement across all channels
        - Get Rare Aware driving political awareness
        - I am Number 17 driving public awareness
    - Oireachtas All Party Group
        - Deep dive into relevant topics with specific asks of TDs & Senators for follow-up.
        - RDI providing secretariat.
        - Topics vary from meeting to meeting
    - Manifesto for Rare Diseases
        - launched in advance of general election
        - 4 thematic areas
    - Budget 2025
        - allocation €1.5m to rare diseases
        - additional €5m allocated subsequent to budget
    - RDCat HRB grant supporting
        - Establishment of Irish patient Advocacy Group (IPAG)
        - Development Patient Reported Experience Measure
        - Investigate role for Patient Centred Outcome Measures to support patient submissions for reimbursement
    - National Rare Disease Strategy
        - Launched by Minister August 2025
        - Implementation and monitoring groups will include PLWRD
        - 3 critical recommendations for impact on lived experience –
            - Screening & Diagnosis
            - Eligibility, access and integration of health services across life course
            - Orphan medicines
- Questions/comments
    - A Lawlor highlighted patient partnership being embedded into HSE
    - C McGrath highlighted role of DFI across many groups and desire to hear from RD community
    - P Towey questioned how €5m additional funding is being allocated to RD services

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