

Annual General Meeting - Minutes

Time: 12.00 pm (noon), Oct 10, 2022

Venue: On-line via Zoom

In Attendance:

Board of Directors (Trustees): John McCormack (acting Chair), Mairead Hennessy (Treasurer), Anne Lawlor, Patricia Towey, Anne Micks, Laura Egan, Paula Guerin

RDI: Vicky McGrath (CEO, RDI)

RD Community:

Kennedy (SOUND), Walsh (RIFSN), Ward (FB), Phair (Cavernoma Ireland), Stuart (MSA), Brennan (PWSAI), Moran (FB), Forde (IHA), Gavin (EDS/HSD), Cassidy (family), P Lynam (family), Almeamar (SVUH), Hennessy (OpenApp), Hannon (BioMarin), Kelly Bryer (Horizon), O'Reilly (Novartis), Magny (Alexion), Morgan (Takeda), R McMenamin (??), K Acrich (??)

Apologies: Michael Blighe (Secretary)

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 – AL propose & MH second
- 2021 AGM minutes – PT propose & PG second
- 2021 Accounts presented by MH
 - Funding remains challenging. Continuing work to diversify sources.
 - Noted projected reduction in reserves at end of 2022 as compared to 2021, due to lumpy nature of project funding and carryover from one year to the next.
 - Approve 2021 audited accounts - AL propose & PT second
 - Reappoint Auditors for FY 2022 – carried via show of hands.
 - Explore options for new-auditors for FY 2023.
- Board
 - Laura Egan – elected to Board – carried via show of hands.
 - Kevin Whelan, David Barton & Michael Blighe retired.
 - Michael Blighe re-election for a 2nd term - carried via show of hands.
 - Thanks to Kevin Whelan and David Barton for their service.

- Updated membership criteria & 2022-25 strategy presented by VM
 - Proposed change to membership criteria so 'Unregulated' patient organisations/groups could become associate members – carried via show of hands.
 - Reviewed 2022-2025 strategy as approved by board
 - Vision is equity for people living with rare diseases in Ireland – equitable access to diagnosis, treatment, health and social care and opportunity.
 - Objectives are to grow awareness, listen to the 300,000 PLWRD, become recognised as united voice for PLWRD, conduct research & promote policies & plans.
- Overview of 2021/22 activities provided by VM
 - Increasing awareness campaigns at Rare Disease Day with Raise A Toastie & LightUp4RD
 - Launch of research (Rare Reality Jan 22 & NBS survey May 22)
 - Commence research on Clinical Genetics services with PIs SAL & JOB
 - Care Pathways development progressing with NRDO
 - Supporting patient submissions for reimbursement
 - Evolving strategy at RDI to address whole person – Health, education, employment, discrimination, transport & housing – looking towards output of EURORDIS Rare2030
 - RD Forum established as follow on for RD Taskforce to discuss on an all-island basis topics of relevance to the community via 3x on-line public webinars each year.
 - Continuing interaction with Gov't, policy makers, DoH, TDs to bring forward promised RD Plan (aligned to Rare 2030 goals).
 - Achieved endorsement for UN Resolution for PLWRD
 - Outlined early plans for 2023 & beyond

- AGM closed -