

19th October 2023

2023 Annual General Meeting Annual General Meeting - Minutes

Time: 12.00 pm (noon), Oct 9, 2023

Venue: On-line via Zoom

In Attendance:

Board of Directors (Trustees): J McCormack (acting Chair), M Hennessy (Treasurer), A Lawlor, P Towey, A Micks, L Egan, M Blighe, P Guerin, A Daly, S O'Reilly

RDI: Vicky McGrath (CEO, RDI)

RD Community:

A Gough (Behcet's), R Bermingham (FB), F Griffin (NFI), D Dunne (CI), M Sweeney (AFI), L Walsh (RI), R Pathrose (FCS focus), N McGrath (FARA Ireland), M Boushel (MPS), S Phair (CI), J Cahalane, D Woods (HHT), D Stuart (MSA) R Jackson (Debra)

L Perkin (UCB), C MacGloinn (Roche), E Rigby (Horizon),

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
- 2022 AGM minutes – AL propose & PG second
- 2022 Accounts presented by MH
 - Funding remains challenging. Continuing work to diversify sources. HRB grant awarded; starting end 2023/2024.
 - Noted projected funds held at end of 2023 as compared to 2022. Year-on-year variation due to lumpy nature of project funding and carryover from one year to the next, but moving generally in the right direction.
 - Approve 2022 audited accounts - AL propose & AD second

- Auditor review and appointment by MH
 - Existing auditor has good controls in place to avoid any conflicts or perception thereof. Cost of appointing a new auditor high. Given controls in place and limited finances recommended reappointment of McCloskey & Sons.
 - Reappoint Auditors for FY 2023 – carried via show of hands.
- Board renewal
 - Patricia Towey, Mairead Hennessy, John McCormack retired.
 - Thanks to Patricia Towey for her service.
 - Mairead Hennessy, John McCormack re-elected for a 2nd term – DD propose, PT seconded.
 - Avril Daly & Susanne O'Reilly– elected to Board – DD propose, PT seconded.
- Reminded all of RDI vision and membership criteria
- Overview of 2022/23 activities provided by VM
 - Continuing to grow awareness campaigns at Rare Disease Day with Raise A Toastie & LightUp4RD and multiple media opportunities over period.
 - Line in the sand with launch of Rare Reality Jan 22 & NBS survey May 22
 - Research on Clinical Genetics services shows that there is huge adverse impact on people waiting to access genetic services.
 - Genetic and genomics strategy published Dec 2022 has begun to be implemented in 2023. Recommended people join upcoming webinars.
 - Care Pathways development progressing with NRDO – 9 approved by HSE's SLT, with a further 3 due for approval before end 2023. CP development has involved multiple stakeholders across HSE, NRDO, HCPs, allied HCPs, PLWRD & patient orgs. Seeking continued input from patient groups to support this work. Next step is securing funding.
 - Get Rare Aware campaign launched in 2023 – focus is genetic services.
 - Rare Disease All Party Group launched at Oireachtas – 3 meetings held to date.
 - RD Catalyst HRG grant awarded – will involve research on Patient centred outcome measures (PCOMs) and Patient Reported Experience Measures (PREMs) and establishment of Irish Patient Advisory Group (IPAG) mirroring ERN structure.
 - Anticipate Rare Disease Steering Group will be launched by DoH before year end.