

Annual General Meeting - Minutes

Time: 12.00 pm (noon), Oct 19, 2021

Venue: On-line via Zoom

In Attendance:

Board of Directors (Trustees): Paula Guerin (acting Chair), Mairead Hennessy (Treasurer), Anne Lawlor, David Barton, Patricia Towey, Anne Micks

RDI: Vicky McGrath (CEO, RDI)

RD Community: B Gilroy (PKUAI), McGrath (DFI), Woods (HHT Ireland), Dunne (???), Fergal (NF Ireland), Power (VIA), Dolan (SOUND), Wogu (SCT Ireland), Neylin (SCIG), Healy (MDI), Vasseghi (TSC Ireland), Byrne (CFI), Phair (Cavernoma Ireland), O'Grady (SMA Ireland), Fearon (Debra Ireland), Milofsky (SWAN Ireland), Kearney (EPAG), Badger (Illumina), Hennessy (OpenApp), Hanrahan (JnJ), Mason (PTC), MacNeice (Horizon), Hayes (KyowKirin)

Apologies: Kevin Whelan (Chair), Michael Blighe (Secretary), John McCormack (Board), Eleanor Hannon (BioMarin),

Minutes

- No conflicts to declare
- Welcome from Kevin Whelan, Chair RDI – thanks to RD community for sharing their time with RDI – via pre-recorded video
- Approval of Agenda – DB propose & MH second
- 2020 AGM minutes – AL propose & DB second
 - VM noted that patient organisation membership fees have not changed, as previously proposed. Renewal date moving to January.
- 2020 Accounts
 - Improving position compared to previous years and forecast for 2021 – increased revenues due to increased memberships and donations.
 - Approve 2020 audited accounts - AL propose & PT second
 - Reappoint Auditors – carried via show of hands.
- Board
 - Anne Micks – elected to Board – carried via show of hands.
 - John McCormack – elected to Board – carried via show of hands.
 - Paula Guerin – re-election – carried via show of hands.
 - Anne Lawlor – re-election – carried via show of hands.

- Overview of 2020 activities provided by VM
 - Increasing awareness campaigns at Rare Disease Day & launch of COVID report.
 - Pledge4RD – general election campaign
 - Rare Disease Day – launch of Easyguide to Rare Diseases & family party at Áras an Uachtaráin
 - Coronavirus – Research report on impact of COVID; COVID-19 Vaccine prioritisation.
 - Evolving strategy at RDI to address whole person – Health, education, employment, discrimination, transport & housing – looking towards output of EURORDIS Rare2030
 - 2021/22 activities & plans - Awareness, Research (Rare Reality Surveys), Rare Disease Plan
- Anne Lawlor – Highlighted the challenges of living with a rare condition and the need for care coordinators
- Mary Kearney – Asked how GPs can access genetic testing directly- previous pathways seem to have disappeared. VM follow-up directly.
- Jonathan O’Grady – spoke of Beneluxa success for Zolgensma – recommended as a pathway to reimbursement for new therapies. There is a need generally for services to support treatment (e.g. physiotherapy for SMA) & need for NBS for SMA.
- Bernadette Gilroy – proper reimbursement system required – therapy still not available for adults even though approved for all.
- Vicky McGrath – continuing search for new members to add to Board.

- **AGM closed** -