

12-10-2020

Annual General Meeting - Minutes

Time: 10.00 am, Oct 1, 2020

Venue: On-line via Zoom

In Attendance:

Board of Directors (Trustees): Kevin Whelan (Chair), Mairead Hennessy (Treasurer), Anne Lawlor (Secretary), David Barton, Paula Guerin, Michael Blighe

RDI: Vicky McGrath (CEO, RDI)

RD Community: John McCormack (Advocate), Les Martin (Advocate), Stacey Grealish (Advocate), Hazel McGeough (SBHI), Sandra Phair (Cavernoma Ireland), Denise Dunne (Cystinosis Ireland), Robert Brady (Pituitary Foundation), Lyndsey Walsh RIFSN???, Talent Nyamakope (SBHI), Katie Dolan (SOUND), Patricia Ryan (Vaculitis Ireland), Alan Finglas (MSD Action), Suja Somanadhan (UCD School medicine), Eleanor Hannon (BioMarin), Suzanne O'Reilly (Novartis), Maureen Mason (PTC Therapeutics), Clare Jordan (Roche), Declan Kinahan (MAP Biopharma)

Apologies: Patricia Towey (Trustee)

Minutes

- No conflicts to declare
- Welcome from Kevin Whelan, Chair RDI – thanks to RD community for sharing their time with RDI.
- Approval of Agenda – DB propose & AL second
- 2019 AGM minutes – DB propose & MH second
- Board
 - Mairead Hennessy – election - AL propose & PG second
 - Michael Blighe – election - DB propose & PG second
 - Patricia Towey – re-election – DD propose & MH second
 - Mary Kearney – stepping down from Board
 - We would like to continue add to our Board membership, particularly anyone living with a rare condition.

- Finances
 - Better position compared to previous years – increased memberships and donations means increased revenues.
 - Increase in expenditure as a result of payroll costs compared to previous years.
 - We will conduct a review of membership fees of patient organisations for 2021
 - Approve 2019 audited accounts - PG propose & MB second
 - Reappoint Auditors – MH proposed & DB second

- Overview of 2019 activities provided by VM
 - Strategy workshop held with patient organisation memberships. Key areas to address – Awareness, Diagnosis, Treatment, Medicines, Services and Research & Registries
 - Awareness – Rare Disease Day (end Feb)
 - RD Research seminar and Raindrop research and publication
 - NRDO, NCPRD & ERN submissions
 - EU MEP election campaign

- Thanks to Les Martin for his tireless work advocating for NBS and enabling an event at Áras an Uachtaráin for the RD Community at Rare Disease Day 2020
- Alan Finglas highlighted the value of ERNs and the need to adopt care pathways from them.
- KW reiterated our commitment to work towards improving the quality of life of those living with rare conditions in Ireland.

- AGM closed -