

### Avril Daly



Avril Daly is the Chair of Rare Diseases Ireland and Vice-President on the Board of Directors at EURORDIS - Rare Diseases Europe.

Avril is the CEO of Retina International, the global patient-led umbrella group dedicated to the promotion of research into rare and inherited as well as age-related forms of retinal degenerative conditions. She previously held the position of CEO at Fighting Blindness Ireland for eight years.

Avril was appointed in 2011 by then Minister for Health to the Steering Committee working towards the development of the Irish National Plan for Rare Diseases, published in 2014. Avril now sits on the Oversight Committee reviewing the implementation of that plan and on the working group of the Clinical Programme for Rare Diseases at the Health Service Executive (HSE).

Avril was a founding member of the Boards of Medical Research Charities Group (MRCG) and, the Irish Platform for Patients' Organisations, Science and Industry (IPPOSI). She served two terms as Board Member of the European Patient's Forum (EPF) and as Board member of European Platform for Patient Organisations Science and Industry (EPPOSI).

Avril Daly was elected to the EURORDIS Board of Directors in 2009, and has been Vice-President of EURORDIS since 2012. She represents EURORDIS at International Conferences throughout Europe and beyond.

Avril is a Business & Media Studies Graduate. She was diagnosed with the rare retinal condition Retinitis Pigmentosa in 1998.