



[Press release]

## Recipients of the EURORDIS Black Pearl Awards 2019 announced

[#EURORDISAwards2019](#) [#BlackPearl](#)

**14 November 2018, Paris** - EURORDIS is pleased to announce the recipients of the 2019 EURORDIS Black Pearl Awards as:

EURORDIS Young Patient Advocate: [Laëtitia Ouillade, France](#)

EURORDIS European Rare Disease Leadership Award: [Prof. Till Voigtländer, Austria](#)

EURORDIS Policy Maker Award: [Dr Edmund Jessop, UK](#)

EURORDIS Scientific Award: [Prof. Philip Van Damme, Belgium](#)

EURORDIS Volunteer Awards:

[Richard West, Behçet's Syndrome Society, UK](#)

[Russell Wheeler, Leber's Hereditary Optic Neuropathy \(LHON\) Society, UK](#)

EURORDIS Members Award: [ALS Liga Belgium](#)

EURORDIS Company Award for Innovation: [Chiesi, Italy](#)

EURORDIS Company Award for Patient Engagement: [The HERCULES Project \(Pfizer Inc, PTC Therapeutics, Roche, Sarepta Therapeutics, Solid Biosciences, Summit Therapeutics, Wave Life Sciences and Duchenne UK\)](#)

EURORDIS Company Award for Health Technology: [Air Liquide Medical Systems, France](#)

EURORDIS Visual and Audio Media Award: ['Et Les Mistrals Gagnants', Anne-Dauphine Julliard, France](#)

EURORDIS Written Media Award: ['Word for Life', Bojana Miroslavljević, Serbia](#)

EURORDIS Lifetime Achievement Award: [Michael Griffith, Ireland](#)

The EURORDIS Black Pearl Awards Ceremony takes place in February to mark the occasion of [Rare Disease Day](#). The Black Pearl Awards recognise the major achievements and outstanding commitment of patient advocates, patient organisations, policy makers, scientists, companies and media who strive to make a difference for the rare disease community. Nominations were submitted by the general public, shortlisted by an ad-hoc nominations committee and then final recipients were selected by the EURORDIS Board of Directors. There were **hundreds of nominations from over 37 different countries** worldwide. The [Black Pearl Awards](#) will be presented to the winners at the Awards Ceremony on 12 February at Le Plaza Hotel, Brussels. Organisations that would like to support or partner with the EURORDIS Black Pearl Awards can find out how [here](#).



## The EURORDIS Photo Award

The EURORDIS Photo Award is open to everyone around the world. It is an opportunity to visually express the reality of living with a rare disease, the joy and the challenges. Last year, nearly 400 people from more than 50 countries around the world submitted a photo. After online submissions close on 7 January, world-renowned National Geographic photojournalist Marcus Bleasdale will shortlist five photos for the public vote. Online voting will open on 15 January via [blackpearl.eurordis.org](#). The winner will be announced live at the EURORDIS Black Pearl Awards on 12 February. The three finalists with the most votes will each receive a prize. See [last year's winner](#) for inspiration.

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## EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 800 rare disease patient organisations from more than 70 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe.

By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services. Follow [@eurordis](#) or see the [EURORDIS Facebook page](#). For more information, visit [eurordis.org](#).

## Rare diseases

The European Union considers a disease as rare when it affects less than 1 in 2,000 citizens. Over 6,000 different rare diseases have been identified to date, affecting an estimated 30 million people in Europe and 300 million worldwide. Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offering inadequate and research limited. Despite their great overall number, rare disease patients are the orphans of health systems, often denied diagnosis, treatment and the benefits of research.

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