



## Announcement: Recipients of the EURORDIS Black Pearl Awards 2020

[#EURORDISAwards2020](#)

**11 December 2019, Paris** – EURORDIS-Rare Diseases Europe congratulates the recipients of the EURORDIS Black Pearl Awards 2020, announced today and listed below.

The Black Pearl Awards are presented to the stars of the rare disease community - patient advocates, organisations, policy makers, scientists, companies and media - for their major achievements and their outstanding commitment to improving the lives of people affected by a rare disease.

Nominations are submitted by the general public, shortlisted by a nominations committee and then selected by the EURORDIS Board of Directors. This year, hundreds of nominations were received from around the world.

Holistic Care Award: [EB-Haus \(Austria\)](#)

Young Patient Advocate Award: [Jana Popova \(Bulgaria\)](#)

European Rare Disease Leadership Award: [Dr. Daria Julkowska \(France/Poland\)](#)

Policy Maker Award: [Dr. Vytenis Andriukaitis \(Lithuania\)](#)

Scientific Award: [Prof. Annemieke Aartsma-Rus \(The Netherlands\)](#)

EURORDIS Volunteer Award: [Claudia Crocione \(Italy\)](#)

Visual & Audio Media Award: [Tomasz Śliwiński & Magda Hueckel \(Poland\)](#)

Written Media Award: [Dr. Lisa Sanders \(USA\)](#)

EURORDIS Members Award: [ALAN - Maladies Rares Luxembourg](#)

Company Award for Innovation: [Healx \(UK\)](#)

Company Award for Health Technology: [TOBEA \(Greece\)](#)

Company Award for Patient Engagement: [Boehringer Ingelheim \(Germany\)](#)

**Read more about each EURORDIS Black Pearl Awardee and their work:**

[blackpearl.eurordis.org/awardees](https://blackpearl.eurordis.org/awardees)

The Awardees will receive their awards at the EURORDIS Black Pearl Awards Ceremony on 18 February 2020 at the Hotel Le Plaza Brussels, held to mark the occasion of Rare Disease Day. To watch the ceremony live online visit [blackpearl.eurordis.org](https://blackpearl.eurordis.org) or [attend in person](#).

## The EURORDIS Photo Award 2020

The EURORDIS Photo Award, the final Black Pearl Award, is currently open for submissions to everyone around the world. It is an opportunity to visually express the reality of living with a rare disease, both the joy and the challenges.

**[Submit your photo by 16 January!](#)**

Renowned National Geographic photographer Marcus Bleasdale will shortlist five finalist photos that will be open to an online public vote in February. The winner will be announced live during the EURORDIS Black Pearl Awards Ceremony. Prizes will be awarded to the winning photographer and runners-up.

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### About 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](http://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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