



EURORDIS announced the recipients of the 2022 Black Pearl Awards

16 February, Paris – EURORDIS-Rare Diseases Europe is pleased to announce the recipients of the 2022 Black Pearl Awards:

Media Award – [EwenLife](#)

Members Award – [Childhood Cancer International Europe \(CCI-E\)](#)

Lifetime Achievement Award – [Dr. William Gahl](#)

Volunteer Award – [Graham Slater](#)

Company Award for Patient Engagement – [European Alliance for Newborn Screening in SMA](#)

Company Award for Health Technology – [Aparito](#)

EURORDIS Company Award for Innovation – [Lysogene](#)

Policy Maker Award – [Prof. Hans-Georg Eichler](#)

Scientific Award – [Prof. Franz Schaefer](#)

Leadership Award – [Dr. Anne-Sophie Lapointe](#)

Young Patient Advocate Award – [Danielle Drachmann](#)

Social Media Award – [my.baby.noa by Milica and Noa](#)

Photo Award – [Smiling underwater by Catarina Costa Duarte \(First place\)](#), [Dalmatian\(s\) by Lucía Lamata \(Second place\)](#), and [Federico by Emiliano Cribari \(Third place\)](#).

The 11th edition of the Black Pearl Awards took place on 8 February, bringing together 377 people from 39 countries. Hosted by BAFTA award-winning broadcaster, vocal coach and advocate, Dr Carrie Grant, the celebration featured appearances by the Black Pearl Awards Honorary Chairperson Dr. Ewa Kopacz, Vice-President of the European Parliament, and a variety of prominent personalities and special guests including Clément Beaune, France's Minister of State for European Affairs, dancer and choreographer Suzie Birchwood, and singer-songwriter Chloe Temtchine.

The ceremony was organised thanks to the support of a broad set of stakeholders – the members of the Black Pearl Committee, individual contributors, outreach partners, and corporate donors – who have helped to make a difference in the lives of people with rare diseases and their families.

Special thanks go to our corporate donors, including Biogen, Janssen, Roche and Takeda, for their support towards the event.

EURORDIS Black Pearl Awards

The EURORDIS Black Pearl Awards Ceremony takes place in February to mark the occasion of [Rare Disease Day](#).

Hailed as EURORDIS' highest honour, the Black Pearl Awards are presented to individuals, organisations and companies who dedicate their lives to making a difference for the rare disease community. Chaired by prominent European policy makers, it brings together all members of the rare disease community – people living with a rare disease, their families, patient advocates, patient organisations, researchers, media, and industry.

Since 2012, this annual ceremony's outreach and notoriety has grown tremendously, and the value of the awards continue to inspire every member of the rare disease community. For more information, please visit blackpearl.eurordis.org.

EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of 956 rare disease patient organisations from 73 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.

Press contact

Stanislav Ostapenko,
Communications Manager
EURORDIS-Rare Diseases Europe
stanislav.ostapenko@eurordis.org
+33 1 56 53 52 61