

Press release

EURORDIS celebrates heroes of European rare disease community at annual Black Pearl Awards

21 February, Brussels – EURORDIS-Rare Diseases Europe is proud to announce the successful conclusion of the 2023 Black Pearl Awards.

The awards – which were attended by over 400 people representing 34 countries both on-site in Brussels and connected online, including patients, healthcare professionals, industry leaders, and policymakers – recognise the achievements of individuals and organisations from right across the rare disease community.

Yann Le Cam, Chief Executive Officer of EURORDIS, expressed his appreciation for the awardees and their contributions to the rare disease community.

"The EURORDIS Black Pearl Awards are a tribute to the heroes of the rare disease community, who are dedicated to making a positive impact in the lives of patients and their families. I would like to extend my warmest congratulations to all the awardees, who have demonstrated exceptional leadership, innovation, and compassion."

- Yann Le Cam, Chief Executive Officer, EURORDIS-Rare Diseases Europe

The official Master of Ceremony for the EURORDIS Black Pearl Awards, **Dr. Carrie Grant**, also lauded the awardees for their outstanding achievements.

"It is a privilege to be part of an event that celebrates the achievements of so many, from those who have been active on the ground supporting Ukrainians living with a rare condition affected by the war, to those who have embraced patient involvement in scientific research and advancement, to those who have movingly captured life with a rare disease in cinema and photography. The awardees are a testament to the resilience and determination of patients, caregivers, and advocates, who are making a significant difference in the lives of millions of people living with rare diseases."

- Dr. Carrie Grant MBE, broadcaster, vocal coach, advocate and Master of Ceremony for the Black Pearl Awards

Among the Black Pearl awardees was **Terkel Andersen**, recipient of the EURORDIS Lifetime Achievement Award, who served as President of EURORDIS for almost 20 years until he stepped down from the position in November 2022.

Additional awardees celebrated at the EURORDIS Black Pearl Awards include:

- **Orphan Diseases of Ukraine**, EURORDIS Members Award
- **Michela Onali**, EURORDIS Volunteer Award.
- **Adrian Goretzki**, EURORDIS Young Patient Advocate Award.
- **Dr Luisa-María Botella Cubells**, EURORDIS Scientific Award
- **Dr Holm Graessner**, EURORDIS Leadership Award
- **Dr Stelios Kypourouopoulos**, EURORDIS Policy Maker Award
- **Amryt Pharma**, EURORDIS Company Award for Patient Engagement
- **PTC Therapeutics**, EURORDIS Company Award for Innovation
- **Mendelian**, EURORDIS Company Award for Health Technology
- **Nicole Faccio**, EURORDIS Social Media Award

- **'Raising Rare'**, photographed by **Lindsay Norman**, EURORDIS Photo Award

The EURORDIS Black Pearl Awards represent an important moment for the rare disease community, as not only do awardees feel honoured by the acknowledgement of their excellent work: they also report feeling motivated and encouraged to continue their commitments to improving the lives of people living with a rare disease.

About EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of more than 1,000 rare disease patient organisations from 74 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](https://twitter.com/eurordis) or see the [EURORDIS Facebook page](https://www.facebook.com/eurordis). For more information, visit eurordis.org.

Press contact

Julien Poulain
Communications Manager
EURORDIS-Rare Diseases Europe
Julien.poulain@eurordis.org
+33 6 42 98 14 32