



## Press release

# Black Pearl Awards 2024: EURORDIS honours champions of rare disease community

**20 February, Brussels** – EURORDIS-Rare Diseases Europe is delighted to announce the successful culmination of the Black Pearl Awards 2024, alongside the complete list of this year's honoured recipients.

The ceremony, hosted both in Brussels and online, gathered hundreds from across the European and international rare disease community.

The event was attended by hundreds of participants from 40 countries, including patient advocates, healthcare professionals, industry stakeholders, policymakers, and artists.

Held each year in February, the EURORDIS Black Pearl Awards are held to commemorate Rare Disease Day – the global campaign aimed at fostering equity for the 300 million individuals globally living with a rare disease. The Rare Disease Day campaign, coordinated by EURORDIS, plays a crucial role in elevating awareness and promoting advocacy.

In the lead-up to Rare Disease Day – this year observed on 29 February – the Black Pearl Awards serve a dual purpose. They not only recognise and honour the exceptional contributions, accomplishments, and relentless commitment of those from across the vast rare disease community but also play a pivotal role in raising funds for the Rare Disease Day campaign, thereby directly supporting the rare disease community at large.

Following nine in-person and two virtual editions during the COVID-19 pandemic, the awards transitioned to a hybrid format for the first time in February 2023. This change has allowed the ceremony to blossom into an increasingly global event, with this year witnessing its highest attendance to date.

**Yann Le Cam**, attending his final Black Pearl Awards as Chief Executive Officer of EURORDIS before he steps down next month from the position after over 20 years, expressed his deep appreciation to the honourees for their invaluable contributions to the rare disease community. Yann remarked:

"I extend my heartfelt congratulations to each of this year's remarkable awardees, whose endeavours have once again showcased the rare disease community's extraordinary leadership, innovation, and empathy. Together, the achievements of this year's recipients have significantly advanced our collective pursuit of a more equitable world for those living with rare diseases.

"This year, we honour those who have provided critical support in crisis zones such as Ukraine, Turkey, and Syria, and those who have pioneered scientific breakthroughs that promise life-changing treatments for genetic conditions. We celebrate those who have diligently advocated for a

comprehensive EU strategy and a solidarity fund for rare diseases, as well as those who have deployed their creative talents – from film to photography and social media – to amplify our community's calls and nurture empathy across broader society.

"Looking ahead, I am optimistic and confident that this year's awardees will continue to propel significant progress for individuals affected by rare diseases. My deepest thanks go to each of them for their lasting contributions, and may their work inspire a growing movement dedicated to our cause in the years ahead."

The individuals and organisations receiving a EURORDIS Black Pearl Award this year were:

- **"Never Stop Moving"** by **Proyecto Alpha**, EURORDIS Media Award
- **Sanofi**, EURORDIS Company Award for Innovation
- **Dr José-Alain Sahel**, EURORDIS Scientific Award
- **DEBRA International**, EURORDIS Members Award
- **Alain Coheur**, EURORDIS Policy Maker Award
- **Silvia Aguilera**, EURORDIS Volunteer Award
- **Adéla Odrihocká**, EURORDIS Young Patient Advocate Award
- **RareResourceNet**, EURORDIS Holistic Care Award
- **Pierre Fabre and EspeRare Foundation**, EURORDIS Company Award for Patient Engagement
- **Poznan Supercomputing and Networking Center**, EURORDIS Company Award for Health Technology
- **Alba Parejo**, EURORDIS Social Media Award
- **Together Strong**, submitted by **Marianne Bal** and photographed by **Melanie Fabi**, EURORDIS Photo Award

## About the EURORDIS Black Pearl Awards

The EURORDIS Black Pearl Awards are named after the extremely rare and precious black pearl, or Tahitian pearl, and they honour the value and uniqueness of people living with rare diseases, and those who effect positive change on their behalf.

## About EURORDIS-Rare Diseases Europe

[EURORDIS-Rare Diseases Europe](#) is a unique, non-profit alliance of over 1,000 rare disease 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 people, families and rare disease 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 services.

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