

Hollywood icon Audrey Hepburn announced as Honorary Patron of EURORDIS-Rare Diseases Europe



Photo of Audrey Hepburn, currently on show at the Intimate Audrey exhibition

29 January 2020, Paris – EURORDIS-Rare Diseases Europe is honoured to announce the late Audrey Hepburn as posthumous Honorary Patron of the organisation.

An Oscar-winning actress, humanitarian and international fashion icon, Ms Hepburn passed away in 1993 from a **rare form of the cancer** pseudomyxoma peritonei (PMP), which affects only one in a million people.

[EURORDIS](#) is a unique, non-profit alliance of 884 rare disease patient organisations from 72 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe.

Sean Hepburn Ferrer, Ms Hepburn's eldest son, is a longstanding supporter of EURORDIS and was Ambassador for Rare Disease Day, the global awareness-raising campaign created by EURORDIS, for five years from 2014 – 2018.

Mr Hepburn Ferrer commented, "I am delighted by the announcement of my mother's patronage of EURORDIS, an organisation that works tirelessly to improve the lives of the hundreds of millions of people affected by rare diseases in Europe and around the world."

He added, "As a family, we had to deal with a long and difficult diagnosis and the loneliness that comes when a rare disease is diagnosed. During my Ambassadorship of Rare Disease Day, I have been astounded by the realisation that no matter what the rare disease, the challenges for patients and their carers are often very similar. These include a crushing loneliness and feeling of isolation, a diagnostic odyssey that can be long and indeed sometimes never-ending, coupled with very few treatments being available to patients living with one of the over 6,000 rare diseases. My mother would be honoured by such an appointment."



Audrey Hepburn and son Sean Hepburn Ferrer

Terkel Andersen, President, EURORDIS, said, “We are continuously grateful for the support from Ms Hepburn’s family to raise awareness of the very real impact that rare diseases have on millions of people and their families every day. We thank Mr Hepburn Ferrer for his dedication to our work and wider cause over the years.”

About Audrey Hepburn

[Read more](#) about Audrey Hepburn.

The **Intimate Audrey exhibition** ran until 31 January in Amsterdam. A celebration of Audrey Hepburn's 90th birthday anniversary year in her home country. 600m2 featuring hundreds of original and re-printed photographs, memorabilia, dresses and accessories as well as her never before seen fashion drawings and humanitarian writings. Visit intimateaudrey.org for more information.

About EURORDIS-Rare Diseases Europe

[EURORDIS-Rare Diseases Europe](#) is a unique, non-profit alliance of over 884 rare disease patient organisations from 72 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 on [Twitter](#), [Facebook](#), [LinkedIn](#) and [Instagram](#).

About 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 over 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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