



PRESS RELEASE

Winners of the EURORDIS Awards 2017 announced

#EURORDISAwards2017

21 February 2017, Brussels – Vytenis Andriukaitis, European Commissioner for Health and Food Safety, this evening presents the EURORDIS Awards 2017 at a ceremony in Brussels.

The EURORDIS Awards & *Black Pearl* Evening is held to mark the occasion of [Rare Disease Day 2017](#). The Awards Ceremony is live streamed from 18:30 CET via eurordis.org/live.

Also in attendance of the event is [Rare Disease Day Ambassador Sean Hepburn Ferrer](#), the eldest son of the late Audrey Hepburn, who passed away from a rare cancer.

The winner of the EURORDIS Awards 2017 are:

Policy Maker Award - [Frédérique Ries, Member of the European Parliament, Belgium](#)

Volunteer Award – [Elizabeth Vroom, Duchenne Parent Project, the Netherlands](#)

Media Award - [Aldo Soligno, Photographer, Rare Lives Project, Italy](#)

Company Award - [GSK - Rare Diseases](#)

Scientific Award - [Dr Lucia Monaco, Chief Scientific Officer Fondazione Telethon, Italy](#)

Patient Organisation Award – [The Dravet Syndrome European Federation, Spain](#)

Lifetime Achievement Award - [Anders Olauson, Founder of the Ågrenska Centre, Sweden](#)

Photos of the award winners are available on the [EURORDIS Flickr page](#).

Elizabeth Vroom, winner of the 2017 Volunteer Award, commented, "Receiving the EURORDIS Volunteer Award is very special, but even more so because this comes from a community I treasure and consider as family. I am very honoured to receive this award as I know how many people like me who work hard to change the lives and future of patients with rare diseases."

Aldo Soligno, winner of the 2017 Media Award, commented, "Spending time with families and patients living with a rare disease has shown me how opposites can meet and transform each other: weakness into strength, sadness into joy, and despair into determination. Seeing this happens simultaneously in seven different European countries has confirmed that there are no boundaries for scientific research and solidarity, and that they must not exist for rare patients. I really hope this will be the legacy of my project."

The purpose of the EURORDIS Awards is to recognise the outstanding commitment and achievements of patient organisations, volunteers, companies, scientists, media and policymakers who have contributed to reducing the impact of rare diseases on people's lives.

For the EURORDIS Awards 2017, nominations were submitted by the general public with the EURORDIS' Board of Directors selecting the winners of each category based on the number and quality of the nominations.

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About the EURORDIS Awards & *Black Pearl Evening*

The EURORDIS Awards and *Black Pearl Evening* serves: to recognise the individuals and organisations that together are improving the lives of people affected by rare diseases; to raise awareness and increase support for the rare disease cause throughout Europe; and to generate funding for EURORDIS programmes. For more information, please visit blackpearl.eurordis.org.

About Rare Disease Day

EURORDIS and its Council of National Alliances launched [Rare Disease Day](#) in 2008. Held on the last day of February each year, a rare day, it seeks to raise awareness of the impact that rare diseases have on the lives of patients and those who care for them. What began as a European event quickly became international in scope, with participants from more countries joining each year.

Since Rare Disease Day began, thousands of events have been held throughout the world, reaching hundreds of thousands of people. The political momentum resulting from the Day has also served advocacy purposes, contributing to the advancement of EU policies on rare diseases and the creation of national plans for rare diseases in a number of EU Member States and now in other countries.

Visit rarediseaseday.org, follow [@rarediseaseday](https://twitter.com/rarediseaseday) or like facebook.com/rarediseaseday.

About EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 700 rare disease patient organisations from more than 60 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](#). For more information, visit eurordis.org.

About Rare Diseases

The European Union considers a disease as rare when it affects fewer than 1 in 2,000 citizens. Over 6000 different rare diseases have been identified to date, affecting over 60 million people in Europe and the USA alone. 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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Full details of EURORDIS Award Winners 2017

Policy Maker Award – Frédérique Ries, Member of the European Parliament, Belgium

Frédérique Ries, Member of the European Parliament since 1999, has been a pioneer in, and a committed advocate for, the implementation of patient-centric health policies that focus on Union added value, of which rare diseases constitute the prime example.

As a member of the Committee on the Environment, Public Health and Food Safety within the European Parliament, Ries' support and groundwork were instrumental in achieving the adoption of the Regulation on Advanced Therapies in 2007. Increasingly campaigning for the rights of patients with rare diseases, she then collaborated with EURORDIS in 2008 to organise the first Public Hearing on Rare Diseases at the European Parliament for Rare Disease Day. In 2015, she presented a written declaration on improving treatment for rare diseases along with other Members of the European Parliament.

Her most recent work, presenting a proposal for a Pilot Project on a Foresight Study on Rare Diseases (Rare 2030) that promotes a continuous bottom-up research approach with participation from all stakeholders including patients, is proof of Ries' dedication towards tackling rare diseases in the European Union. For all of this, she is the unequivocal winner of the EURORDIS Policy Maker Award 2017.

Volunteer Award - Elizabeth Vroom, Duchenne Parent Project, the Netherlands

Elizabeth has received a degree in Dental Medicine from the University of Groningen, before specialising in Maxillofacial Orthopedics and Orthodontics at Radboud University Nijmegen. She uses her expertise to help Duchenne Muscular Dystrophy (DMD) patients with orthodontic problems.

A mother to a son with DMD, she founded the Duchenne Parent Project in the Netherlands, of which she remains President to this day. In 2002, Elizabeth co-founded the United Parent Projects Muscular Dystrophy (UPPMD) and serves as Chair. She has spent over 20 years dedicating her efforts to raising awareness, to raising funds, to educating and to working to see that patients receive optimal care, as well as worked internationally to help set up patient organisations.

She has served on a number of advisory boards for patient care, research, ethics, development of new medicines and regulatory issues in the Netherlands as well as on pan-European ones. She has also been a member of EURORDIS' RD-Connect Joint Patient Advisory Council and currently chairs the TREAT-NMD Project Ethics Council.

Elizabeth shared her expertise at EURORDIS' 2015 and 2016 Summer Schools. EURORDIS' Summer School aims to empower patient's representatives in the areas of clinical trials and EU regulatory affairs.

Elizabeth established the World Duchenne Awareness day. All those who joined to celebrate this day in 2016: 88 advocacy groups in 40 countries, have highlighted its success. This Award serves to recognise all that Elizabeth has accomplished in supporting so many rare disease organisations and her longstanding commitment.

Media Award - Aldo Soligno, Photographer, Rare Lives Project, Italy

Aldo Soligno is an emerging talent in Italian documentary photography. In October 2014, he led the project 'Rare Lives', a powerful photographic storytelling tool that gives an insight into the daily lives

of people living with a rare disease. It investigates the needs, hopes, difficulties, but above all, the joys and daily achievements of those living a 'rare life'. This project was carried out through home visits to 28 families in 7 European countries thanks to the collaboration with UNIAMO, the Italian Federation of Rare Disease associations. Through Aldo's work, he has inspired other projects, such as #MaketoCare, that in turn, have placed a spotlight on the rare disease community. The project was published in six major European magazines and was the object of several talks and presentations. It was also broadcast on the Italian national television channel RAI.

Aldo receives the Media Award for his dedication and continued efforts to increase the visibility of people living with a rare disease.

Company Award - GSK - Rare Diseases

GSK is one of the world's largest pharmaceutical companies, developing pharmaceuticals, vaccines and consumer healthcare products. Beginning in 2010, the Company has dedicated rare diseases as a core therapeutic area. In 2016, years of collaboration between GSK, Fondazione Telethon and Ospedale San Raffaele brought to market an innovative gene therapy to treat patients with the rare disease adenosine deaminase severe combined immunodeficiency syndrome (ADA-SCID). This advancement shows the results of partnership between patient organisations, clinicians, large and small companies to develop and make available treatments to meet unmet needs of rare disease patients.

GSK has been an active member of the EURORDIS Round Table of Companies (ERTC) since 2008 and has supported EURORDIS Membership Meetings, RareConnect, and the launching of the Rare Barometer Programme.

Scientific Award – Dr Lucia Monaco, Chief Scientific Officer Fondazione Telethon, Italy

Dr Lucia Monaco graduated in chemistry at the University of Pavia and received her training in biochemistry at the University of Iowa in Iowa City, USA and in molecular biology at the European Molecular Biology Laboratory in Heidelberg, Germany. Following more than 20 years as a researcher in both the industrial and academic settings, in her role as Chief Scientific Officer at the Fondazione Telethon, she has made significant impact in the field of rare genetic diseases in Italy and abroad, in particular through her strong commitment to the IRDiRC initiative.

Dr Monaco has also shown strategic vision in developing Fondazione Telethon's Rare Disease Programme and linked it with both academic and commercial partners, as well as patient organisations across Europe. She has maintained a significant presence at scientific and patient centred meetings including (IRDiRC), ICORD, and EURORDIS-Rare Diseases Europe. Moreover, she has actively supported and shaped key research infrastructure developments in the field of rare diseases, particularly related to biobanking and data sharing via EuroBioBank and RD-Connect. Her personal enthusiasm, guidance and dedication inspires many scientists and clinicians to become involved in state-of-the-art research for rare diseases including the successful development of gene therapies. The EURORDIS Scientific Award recognises the major impact Dr Monaco's work has had on rare diseases.

Patient Organisation Award - The Dravet Syndrome European Federation, Spain

EURORDIS is especially pleased to present the 2017 EURORDIS Patient Organisation Award to Dravet – the Dravet Syndrome European Federation. Dravet was founded in 2014 by eight patient organisations in seven countries, who have worked together to raise awareness and to fight the

impact of Dravet Syndrome, otherwise known as Severe Myoclonic Epilepsy of Infancy (SMEI), on patients and their families.

The organisation now counts thirteen members and aims to help people in countries without local support and associations for Dravet Syndrome. Among many other actions, Dravet raises awareness about this rare disease, looks for solutions to improve the quality of life of patients and helps countries to create their own association.

Affecting 1 in 20 000 individuals, Dravet continues to stimulate research and development into treatments by specialist physicians and researchers. This incredibly well deserved Award serves to recognise the efforts and successes that have resulted from the hard work and determination of those at Dravet.

Lifetime Achievement Award - Anders Olauson, Founder of the Ågrenska Centre, Sweden

Anders Olauson has devoted the past 30 years of his life to the rare disease cause, notably rare conditions affecting the lives of children and their families. Through personal experience, Mr Olauson comments: "Having a rare disease affects all aspects of life; experiences from thousands of families worldwide tell the same story. All areas of life - healthcare, social services, schools, insurances and labour - must work together. Life is holistic, as should care and support be. Working together at the United Nations will make this possible."

Taking action to provide a platform for people living with a rare disease, Anders helped found the Ågrenska Centre in 1989, a national competence centre based in Sweden providing support for children, teenagers and adults affected by rare diseases. Here, he continues to serve as Chairman and established the Ågrenska Academy, a virtual centre for information, research and the dissemination of knowledge of rare diseases. His work also involves contact with legislative bodies on both a national and regional level, healthcare professionals, education and labour unions and other key players in the field of rare diseases.

Anders brought his enthusiasm and experience to his role as the President of EURORDIS-Rare Diseases Europe in 2000, as well as adherence as a member of the EURORDIS Board of Directors from 1999 to 2010. EURORDIS appointed Anders as its representative at the European Patients' Forum (EPF); elected President from 2005 to 2015, Anders is now the Honorary President of EPF. EPF is active in the field of European public health and health advocacy representing the patient voice on an EU level.

Since 2006, Anders has been a member of the Advisory Group for Health Research within the Directorate-General for Research and Innovation of the European Commission. The Swedish Government also appointed Anders as a member of the Advisory Council at the National Board of Health and Welfare in 2008, serving until 2014.

Anders' continued efforts have led to his involvement with the NGO Committee for Rare Diseases, initiated by Ågrenska and EURORDIS. This committee's objectives are to increase the visibility of rare diseases on a global level, as well as to make rare diseases a priority in public health, research, medical and social care policies. Anders' vision and goals for the rare disease community are reflective of his long-term dedication to rare diseases. EURORDIS is delighted to award Anders with this Lifetime Achievement Award as it serves to honour all that Anders has done for the rare disease community.