Press release

EURORDIS Open Academy wins ESAE Association 'Impact Award' 2023

15 June 2023, Paris – The EURORDIS Open Academy programme has received the ESAE Association 'Impact Award' 2023 for its achievements in driving positive change. The European Society of Association Executives (ESAE) is the leading organisation in Europe for bringing together association professionals. Each year, they reward projects that inspire the community, with the main goal of championing best practices and transferable knowledge.

Since 2008, EURORDIS have offered multiple programmes and courses to patient advocates, empowering not only our member organisations and volunteers, but anyone interested in learning more about the rare disease landscape. By the end of 2022, the programme had reached over 2,650 registered users from more than 155 countries.

> **Sharon Ashton**, **Open Academy & Events Director**, said "One of the core missions and strategic objectives of EURORDIS is to empower patient advocates and build their capacities to enable them to engage with all stakeholders and bring about impactful change for people living with a rare disease at both the national and European levels. We are very pleased to have been recognised for the work we do in empowering patient advocates' knowledge and skills on important issues impacting the lives of people living with rare diseases."

By fostering their expertise, our Open Academy programme enables advocates to contribute effectively to discussions on healthcare, research, and the development of medicines.

The programme is composed of various schools for EURORDIS members, and e-learning courses open to anyone, freely available on the Open Academy training platform. Upon completion of a course or school, participants become members of the Open Academy alumni, joining a network of over 600 people from over 50 countries.

> **Marta Campabadal, Open Academy Manager**, added: "Alumni of the Open Academy engage as equal partners in various initiatives aimed at enhancing care, treatment, and the overall quality of life for people affected by rare diseases, both at the European and national levels."

The flagship initiative of the Open Academy is the 'School on Medicines Research & Development', which aims to help rare disease patient advocates become experts in medicines research and development. Topics covered in the school include clinical trials methodology, clinical research, ethics in medicines development, regulatory affairs, health technology assessment and marketing authorisation, delivered by experts in the field. Since 2015, the school has also welcomed researchers to attend.

> **Marta Campabadal, Open Academy Manager**, commented "Previous participants of the school have used the skills and knowledge learnt to successfully advocate for national healthcare systems to fund rare disease treatment. They have also contributed to Health Technology Assessment (HTA) on a regional and national level among other activities."

In February 2023, EURORDIS ran its second *Rare Disease Week* training that has empowered patient advocates with the knowledge and skills to effectively advocate at the European level and influence EU decisions that have a direct impact on the lives of people living with a rare disease.

In preparation for the week, participants were invited to take an online training course through the Open Academy platform to learn more about the EU institutions and the Ordinary Legislative Procedure of the EU.

EURORDIS welcomes the ESAE Association 'Impact Award' 2023, and will continue to strive to deliver high quality courses for patient advocates, on various topics concerning the rare disease community.

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About EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 1000 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.