

Press release

EURORDIS receives a grant from Boston Scientific Foundation Europe to support the 'Building Good Practices' ePAG Webinar Series

26 January 2022, Paris – EURORDIS-Rare Diseases Europe has been awarded a grant from Boston Scientific Foundation Europe, to support the launch of a webinar series 'Building Good Practices' for European Patient Advocate Groups (ePAGs).

The ePAG webinar series will comprise four quarterly online meetings, for which EURORDIS will source topics and speakers from among the ePAG patient volunteers and oversee the development, presentation, and dissemination of the training sessions.

The main goals of the grant are:

- To support the launch of this webinar series, which will inspire other ePAG advocates to replicate or adapt good practices to their own needs and context, their representation of the rare disease patient community and in turn elevate the two-way communication between patients and the European Reference Networks (ERNs).
- To encourage ePAG advocates to deliver webinars which they have developed to guide others through their own experience, identifying success factors and lessons learned.

"We are resolute in supporting leaders, such as EURORDIS, who are driving change for patients. Digital initiatives can be particularly beneficial to reach smaller patient populations and we fully support the Building Good Practices online skills programme because it perfectly exemplifies our mission, to improve patient wellbeing using innovative solutions. We believe in the value this education will bring the European Patient Advocacy Groups network to elevate the patient voice across the European Reference Networks," says **Sandrine Bazile, President of the Boston Scientific Foundation Europe**.

"In the new European Reference Networks for Rare Diseases, ePAGs and clinicians are the innovators and the social reformers of healthcare. They are changing the patient journey and changing the system, and that will progressively translate into a more formal and more routine public-private partnership," confirms **Yann Le Cam, EURORDIS Chief Executive Officer**. "EURORDIS is committed to empowering patient advocates with capacity building forums online and in-person as together we raise the patient perspective and collaborate as equal partners with other stakeholders."

These webinars are one of EURORDIS' multiple capacity building and training cycles for patient advocates, including EURORDIS' informative website and publications, the [EURORDIS Open Academy](#) and the EURORDIS Membership Meeting workshops to name a few on a large variety of topics relevant to rare diseases, rare disease policy and regulatory aspects.

ePAGs have been coordinated by EURORDIS since the start of the European Reference Networks in 2017. ePAGs bring together elected patient advocates and affiliated organisations who ensure that the patient voice is heard throughout the ERN development process and that patients remain equal partners in the decision-making processes.

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Contact

Brian Howard

Head of Philanthropy & Partnerships at EURORDIS-Rare Diseases Europe

brian.howard@eurordis.org

+33 6 75 69 92 54

About EURORDIS-Rare Diseases Europe

[EURORDIS-Rare Diseases Europe](#) is a unique, non-profit alliance of over 980 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.

About the Boston Scientific Foundation Europe

The Boston Scientific Foundation Europe (BSFE) is a non-profit organisation that supports well-being through digital solutions. Addressing issues of public interest, the Foundation funds initiatives from European non-profit organisations that help prevent or manage diseases. Established in 2018, BSFE is headquartered in France and funded solely by Boston Scientific. For more information, visit BSFE's [website](#) or their [Facebook page](#).

About ePAG advocates

316 ePAG advocates from 21 European countries currently represent the interests of specific rare disease areas and the wider patient community, building a two-way communication between patients and the European Reference Networks (ERNs), and working in partnership with the clinicians and researchers in ERNs to ensure that the needs of people living with a rare disease are included in the strategic and operational delivery of the Networks, providing the patient perspective.